

ACCESS TO EDUCATIONAL AND HEALTH CARE SERVICES
FOR SCHOOL-AGE CHILDREN
WITH ATTENTION-DEFICIT/HYPERACTIVITY DISORDER

BY

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DISSERTATION

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ABSTRACT

Children with attention-deficit/hyperactivity disorder (ADHD) use educational services and health care services for ameliorating its symptoms and problems. Both civil rights legislation and special education legislation support educational services for children with ADHD, but a change in special education legislative policy on ADHD occurred in 1997 that was expected to enable their access to these services. This dissertation research used a legal method to investigate access to educational services surrounding this change. In addition, parents were interviewed in focus groups in order to learn about their perspectives on access to both educational and health care services for children with ADHD. Access to services was conceptualized broadly for the study, as common steps within pathways for entering into the ADHD service delivery system.

The substantive nature of 121 administrative case complaints is described, using problem categories and specific issues within categories. Decision makers consistently interpreted policy in order to resolve these disputes, and findings lend support to the 1997 policy development and its implementation enabling access to special education services for children with ADHD. However, parents in focus groups yet reported problems in access to educational services for their children with ADHD, particularly with school evaluations for determining children's eligibility for services. Study implications are discussed, and strategies for stakeholders are aimed at improving service dissemination. Important focus group findings on access to health care services also emerged, and recommendations are made for improved service access in this pathway. Parents reported problems of stigma within both services, but good communication occurred both within and between services once children began using services.

To my sons

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CHAPTER 1

INTRODUCTION

In this dissertation I have studied access to educational and health care services for children with attention-deficit/hyperactivity disorder (ADHD), a relatively common mental health condition that can cause problems for children at school, at home, and in other areas of their lives. Educational and health care services are available that help ameliorate the symptoms, problems, and consequences stemming from ADHD in children. These two services are the primary services used for problems stemming from children's ADHD and are thought to be interrelated with overlapping service access issues.

I investigated children's access to educational services for ADHD surrounding a change in the special education legislative policy on ADHD, as this change was expected to improve their access to special education services. I used a legal method to study administrative case complaints that were filed mostly by parents who were dissatisfied with educational services for their children with ADHD; I learned about their service access issues from these complaints. This is an area that has not been widely studied. In addition to studying complaints filed, I conducted focus groups with other parents in order to learn about their children's access to ADHD services in both education and health care. These groups were formed years after the change in special education policy affecting ADHD was implemented.

Nature of the Problem

Understanding Attention-Deficit/Hyperactivity Disorder

The 4th edition of the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000) describes attention-deficit/hyperactivity disorder (ADHD) as "a persistent pattern of inattention and/or

hyperactivity-impulsivity that is more frequently displayed and more severe than is typically observed in individuals at a comparable level of development” (p. 85) and includes diagnostic criteria. The diagnostic criteria are not restricted to children and apply to all age groups, with an estimated 3-7% of school-age children having ADHD. The criteria recognize three types of the disorder: predominantly hyperactive-impulsive, predominantly inattentive, and combined type. Further, for all three types, there are additional requirements for diagnosis: (a) some symptoms that cause impairment must have been present before 7 years of age; (b) some impairment from the symptoms must be present in at least two settings (for example, at home and at school or work); and (c) there must be clear evidence of interference with developmentally appropriate social, academic, or occupational functioning. Most children are not diagnosed with ADHD before kindergarten or first grade (DuPaul & Stoner, 2003), and early work by Fowler (1991) recognized that all children with ADHD do not have the disorder to the same degree or intensity.

Problems and Consequences of the Disorder

The symptoms of ADHD are present as occasional behavioral issues with almost every child, but in ADHD these symptoms as well as the associated problems are more severe, pervasive, and clinically significant. In addition to diagnostic criteria, the *DSM-IV-TR* (American Psychiatric Association, 2000) describes the problems associated with children who have ADHD. Children with ADHD may be easily frustrated, moody, and demanding. They may experience rejection from peers and suffer from poor self-esteem. Academic achievement may be difficult for them, and they may consider it unimportant. This can contribute to conflict within the family and at school. Their inability to sustain efforts on tasks may cause others to view them as lazy, irresponsible, and oppositional. Feelings of resentment and antagonism may arise in family members, especially if they mistakenly believe that all of the child’s bothersome

behaviors are deliberate, and negative parent-child relations are not uncommon. According to the National Institutes of Health (2000), the functional impairment of children with ADHD can occur in school, at home, and with peers, and it may have long-term adverse effects on their academic outcomes, social-emotional development, and employment.

Of great concern are the many children diagnosed with ADHD and the educational complications associated with the disorder, including academic underachievement and scholastic failure (Barkley, Fischer, & Edelbrock, 1990). Scholarly efforts drew attention to the educational needs of children with ADHD (Zentall, 1993). More recent literature has reported that even children with subsyndromal ADHD have high rates of educational problems unexplained by intellect or learning disabilities (Volk, Neuman, & Todd, 2005).

Most children and adolescents with ADHD are reported to have at least some academic impairment (Cantwell & Baker, 1991). Developmental factors may impact school evaluations for these children, especially for preschoolers and adolescents (Anastopoulos & Shelton, 2001). An estimated one in four children with ADHD has learning disabilities (Tannock & Brown, 2000). When compared to children without ADHD, children with ADHD are more likely to be expelled or suspended and to repeat a grade, and parents report their children with ADHD to be at a high risk for school failure (LeFever, Villers, & Morrow, 2002). The symptoms of ADHD compromise academic work across the lifespan (DuPaul & Power, 2000).

Services for the Disorder

A clarification of this dissertation's terminology used relative to services for ADHD is important. The terms "intervention," "treatment," "educational method," and "educational strategy" are used throughout this work in referring to corrective ways or means for ameliorating the symptoms, problems, or consequences of ADHD. The word "services" is used collectively to

include any of these terms.

Many different interventions, with varying efficacy levels, are available for children with ADHD. DuPaul and Stoner (2003) described a variety of educational and psychosocial interventions to serve school children with ADHD: classroom behavior management, self-management of behavior, remedial or supplemental instruction, peer tutoring, computer-assisted instruction, task modifications, strategy training, social skills training, coaching teens, parent training, behavioral family therapy, homework interventions, and parent support groups. In health care services, a medical perspective on the treatment of ADHD in children and adolescents recognized many opportunities for intervening (Goldman, Genel, Bezman, & Slanetz, 1998). More recent resources are available to inform practitioners on diagnosing, evaluating, and treating ADHD according to recommended clinical practice guidelines (American Academy of Child and Adolescent Psychiatry, 2007; American Academy of Pediatrics, 2011). Current treatment recommendations from the American Academy of Child and Adolescent Psychiatry (2007) place emphasis on the use of medication, parent education and support, and appropriate school placement.

Service Delivery System for the Disorder

The service delivery system for children with ADHD includes those individuals who provide ADHD services needed by these children or provide these services needed by families of these children, with services provided at varying locations and frequencies. Children with ADHD may receive interventions from teachers (including special education), nurses, physicians, mental health specialists, psychologists, social workers, family service specialists, child welfare specialists, and disability therapists (including recreational, occupational, and speech/language). These service providers may be located in schools, clinics, offices, agencies, institutions, or

departments, operating either publicly or privately. In addition, advocacy groups such as Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD) are part of the service delivery system, providing services such as outreach, education, and support networks.

A range of services can be planned for a child with ADHD, depending on the severity of the disorder (Fowler, 1991) as well as other influences such as the child's intelligence, social competence, coexisting conditions, family resources, and school and community support. The educational services include those services provided or funded by schools and may be related to learning or be psychosocial in nature. The impact of a child's ADHD may be addressed by slight modifications in the child's daily school routine or may require special education services. In health care, services may include both medical care and behavioral or mental health services, provided in private or public/community settings, and costs of the services are covered by health insurance, private payment, or public funding. A child's health care services for ADHD may begin with visiting a physician for assessment and diagnosis. After the diagnosis is made, a recommended treatment plan may include prescription medication, behavioral intervention, and monitoring of school progress.

Legislation Supporting Educational Services

Legislation supports educational services for children with disabilities, and its support of services applicable to children with ADHD is introduced here. There are two important pieces of legislation that affect service provision in schools. First, when it can be demonstrated that ADHD substantially limits a child's ability to learn, access to educational services is available in the form of accommodations and modifications under Section 504 of the Rehabilitation Act of 1973 (Section 504) (P.L. 93-112). Second, extension of the other health impairment (OHI) disability classification under the Individuals with Disabilities Education Act Amendments of 1997 (IDEA

97) (P.L. 105-17) specifically included ADHD. Following IDEA 97, children with ADHD have been legally eligible to receive special education and related services under OHI due to their ADHD if it is determined that they require these services for problems at school. As with all disabilities, receiving special education and related services for ADHD requires that a child's ADHD is found to adversely affect the child's educational performance.

Problems within the ADHD Service Delivery System

A child with ADHD should have been able to receive special education services under IDEA 97 due to the condition of ADHD if the child met the eligibility criteria of (a) having a diagnosis of ADHD and (b) an evaluation for special education services determined that the disability from the condition of ADHD adversely affected the child's educational performance to require these services. Following the IDEA 97 change in special education legislative policy for children with ADHD, the question remains: Did children with ADHD in fact receive special education services under OHI under IDEA 97 when an evaluation found that they required these services due to their ADHD? Parents have sometimes had problems obtaining special education services for their children with ADHD, problems within the areas of eligibility for services, evaluation, change-of-placement, and sufficiency of services (Underwood & Kopels, 2004). Children with ADHD who do not receive special education services may still need other educational supports. According to Forness (1998), more than half of children with ADHD may not receive special education services and will either receive educational services under Section 504 or receive no educational services.

In health care, researchers have also identified problems in access to services for children with ADHD. Difficulty with differentially diagnosing ADHD from other mental health problems such as anxiety (Desgranges, Desgranges, & Karsky, 1995; Kearney & Kearney, 1998),

depression, or behavior disorders (Desgranges et al., 1995) can impact access to appropriate treatment. Other scholars have reported underutilization of health care services by children with ADHD (Bussing, Zima, Perwien, Belin, & Widawski, 1998; Eiraldi, Mazzuca, Clarke, & Power, 2006; Hoagwood, Kelleher, Feil, & Comer, 2000; Reich, Huang, & Todd, 2006). Bussing et al. (1998) found that 44% of a sample of children in special education who were in grades two through four met the medical diagnostic criteria for ADHD. Yet among that 44%, only half were actually receiving health care services for the condition of ADHD. According to Hoagwood et al. (2000), only about half of children with ADHD received health care services that corresponded to recommended clinical practice guidelines, and service access barriers were identified that included a lack of specialists, insurance issues, and wait lists for appointments. Finally, ADHD can be a financial burden for families because health insurance may not cover the disorder's health care costs (National Institutes of Health, 2000). Underwood and Anderson (2004) reported that parents were concerned about personal paying for health care services that the parents perceived to be necessary for their children with ADHD. A family with low income carries an additional burden related to paying for these services, and this can add stressors to a family already coping with a child's ADHD.

Study Purpose and Research Area

The purpose of this study was to investigate access to educational services for children with ADHD during a period of time that surrounded a change in special education legislative policy expected to favor their service access and also to learn parents' perspectives on access to ADHD services in education and health care for their children. Access to services was conceptualized broadly for the dissertation: taking service-seeking steps in screening, identification, referral, and service utilization of service pathways for entering into service

delivery systems as informed by Powell, Fixsen, Dunlap, Smith, and Fox (2007) and developed in Chapter 2. The intent was to improve our understanding of strengths and weaknesses in these areas of the service delivery system for children with ADHD and to learn about strategies employed when problems were encountered. The questions developed in the research area are presented next.

Research Questions

1. What was the substantive nature of study complaints, as described by problem categories and important service access issues within categories?
2. Did children in later study complaints receive special education services for their ADHD under OHI under IDEA 97 during the final three years studied?
3. During the period of time from 1992-2004, did the proportion of study complaints that were filed under special education change significantly with respect to the implementation of IDEA 97?
4. What did parents, especially those with low incomes, report about their understanding of ADHD and about their children's access to both educational and health care services for ADHD that help ameliorate its effects?

This study built knowledge about parents' abilities to obtain educational and health care services for their children with ADHD. Limited research has been published that reports on administrative case complaints filed regarding educational services for children with ADHD or that uses a longitudinal analysis to examine changes in routes of access for filing these complaints relative to IDEA 97. In addition, learning directly from parents in focus groups about issues they confronted in access to educational and health care services related to their children's

ADHD was useful in building knowledge to inform program and service development for families experiencing similar ADHD issues.

Organization of Dissertation by Chapters

The dissertation is organized with four additional chapters. Chapter 2 is divided into two parts, with the first part used for developing the conceptualization of access to services for the dissertation and for reviewing factors affecting health care service access. In addition, a lens of deductive systems theory is introduced for use in viewing educational and health care services both separately and as interrelated parts of the ADHD service delivery system. In the second part of Chapter 2, background is provided on how legislation supports children's educational services in the ADHD service delivery system, including important historical developments for special education services. Also included in the second part of the chapter is a brief review of the evidence base from which health care services for children with ADHD have developed.

In Chapter 3, a social epidemiology research approach is explained and the methods used for studying the research questions are developed. Details about data collection and analysis are provided. The research findings for the legal and focus group methods are reported separately in Chapter 4. In Chapter 5, these findings are interpreted, discussed, and integrated for study implications that are followed by recommendations for improving service dissemination in the education pathway and for closing gaps in the health care pathway. The chapter closes by recognizing the study's contribution to a better understanding of access to educational and health care services for children with ADHD, particularly regarding educational services following IDEA 97, and areas for future research are suggested.

CHAPTER 2

CONCEPTUALIZATION, LITERATURE REVIEW, AND BACKGROUND

The first part of this chapter is used to conceptualize access to services before studying it in education and health care for children with ADHD. This conceptualization draws from the literature by providing examples of other special populations of children and their entry through representative service pathways into service delivery systems. It reviews literature to synthesize specific factors related to health care service access, but the factors affecting educational service access are considered to be rooted in the legal background that is included later on in the chapter. The conceptualization of access to services ends with an introduction to systems theory that is used in the dissertation as a lens for viewing educational and health care services both separately and as interrelated parts of the service delivery system for children with ADHD.

In Part Two, background is provided on the development of services in education and health care for children with ADHD. The section begins with background on educational services in the context of legal provisions under two separate routes of access for children with disabilities and specific policy development for children with ADHD under special education. This is followed by background on the evidence base from which health care services for children with ADHD have developed.

Part One: Conceptualization of Access to Services

Studying access to services is important, but limitations in defining and conceptualizing access have discouraged generalized understanding and interpretations of study findings in this area (Anderson, Liu, & Zhang, 2007). This section draws from literature that contributed to the conceptual development of access to services for study in this dissertation. It begins with a broad

review of pathways for entering into service delivery systems as used by children in the areas described and then looks at common steps within service access pathways.

Conceptualization of Pathways for Entering into Service Delivery Systems

Literature on access to services describes pathways for children to enter into service delivery systems. Systems pathways have evolved due to legislation, regulations, entitlement programs, mandates, and the existence of various voluntary services. These pathways may include diverse programs, services, and funding streams. Such pathways in service delivery systems for special populations of children have been studied. The focus here is on pathways for children with mental health problems (Farmer, Burns, Phillips, Angold, & Costello, 2003), for children with challenging behaviors (Powell et al., 2007), and for children with child welfare involvement (Burns et al., 2004; Humphrey, Turnbull, & Turnbull, 2006; Hurlburt et al., 2004; Inkelas & Halfon, 2002). Examining pathways of these particular systems is helpful for understanding similar scenarios in service access that parents of children with ADHD might confront, and these special populations likewise may include children with ADHD.

Children's mental health service delivery system. Farmer et al. (2003) have built knowledge about access to the service delivery system for children using mental health services. Their research discussed pathways to these services as service "sectors" and reported on the mental health problems of, and services used by, 1,420 youth from the general youth population. Using data from the longitudinal Great Smoky Mountains Study, Farmer et al. found that during a three year period 33.6% of the youth sample received services to address emotional, behavioral, or substance use problems, but access to these mental health services was gained through different pathways. Services were delivered in five service sectors: education, specialty mental health, general medicine, juvenile justice, and child welfare.

In the study by Farmer et al. (2003), the educational sector provided services most often to children with 24.1% receiving services there. This was followed by the specialty mental health services sector use at 14.2%. Further, for those youth who received services at some time during their lives, more than half first received services through the educational sector. According to Farmer et al., these findings point to the central role that education plays in access to mental health services for youth, both as a point of entry and as a provider of services. They raised questions for further research regarding the role of interagency collaboration, especially among the education, specialty mental health services, and general medicine sectors, to address some observed service patterns such as youth receiving services from more than one sector.

Service delivery system for children with challenging behaviors. Powell et al. (2007) reviewed access to services for young children with or at risk of challenging behaviors and defined challenging behavior as “any repeated pattern of behavior, or perception of behavior, that interferes with or is at risk of interfering with optimal learning or engagement in pro-social interactions with peers and adults” (p. 83). The researchers were concerned about three groups of children who they feel need to be identified early and have access to services: children with disabilities, children at risk for disability, and children at risk for behavioral disorders.

The work by Powell et al. (2007) recognized steps in screening, identification, referral, and utilization as part of the service access process described under five pathways of service delivery: health care, early care and education, child welfare, early intervention and education for children with disabilities, and mental health. The best opportunity for large-scale screening was reported to be within the health care and early care and education sectors, expected to result from the fact that these pathways serve large numbers of children and are open to almost all young children. In addition, programs that serve children living in families with low incomes (for

example, Head Start, public health clinics, Medicaid) are prominent within these pathways, and such children may be more at risk for developing challenging behaviors (Powell et al., 2007).

Three federal programs support health service access for young children living in families with low incomes: Medicaid, the State Children's Health Insurance Program (SCHIP), and the Maternal and Child Health Block Grant (MCHBG) (Powell et al., 2007). Children with Medicaid coverage are entitled to Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services, which are intended to provide access to comprehensive and preventive care services along a seamless pathway, including services in behavioral health. Medicaid is most commonly used, but SCHIP and the MCHBG extend service access to other vulnerable young children not eligible for Medicaid. The MCHBG uses system-building efforts to provide outreach, facilitate services, and coordinate services with Medicaid, but SCHIP extends services by providing children with Medicaid insurance or other publicly funded health care insurance. In addition, the MCHBG can serve children with special health care needs through specialized programs.

Some problems with the implementation of programs were reported by Powell et al. (2007). For example, a lack of sufficient funding may prohibit full implementation of a program. Further, the broad latitude that allows states to interpret and implement federal mandates within service pathways can contribute to inconsistencies in how children are identified and linked to services. The authors maintained that insufficient evidence is available for firm conclusions about effective ways to identify and link to services needed by the group of children they studied. They called for further research to document the availability and use of various services and systems with input on strengths and weaknesses provided by key stakeholders, including families who have young children with or at risk for challenging behaviors.

Service delivery system for children who are child welfare clients. Literature on system pathways also comes from the special population of children who are clients of the child welfare system. Inkelas and Halfon (2002) studied access to services for this group of children. In particular, they evaluated Medicaid policies on eligibility, enrollment, retention, and coverage for physical, dental, developmental, and mental health services. They concluded that there are gaps in services and incomplete coverage. For example, they found that agencies mandated to ensure that children in foster care received health services had problems paying for the children's health services.

Studies examined specific access to mental health services for children who are clients of the child welfare system (Burns et al., 2004; Humphrey et al., 2006; Hurlburt et al., 2004). Almost one-half of youth with completed investigations by child welfare agencies had clinically significant emotional or behavioral problems (Burns et al., 2004). Yet, only one fourth of those evaluated to be within the clinical range for recommended treatment received any specialty mental health care in the previous 12 months. The authors therefore recommended routine mental health screening as well as follow-up from the screening when a child first becomes involved with the child welfare system.

Work by Hurlburt et al. (2004) used data from a nationally representative sample of children who were clients of the child welfare system. They reported persistently high rates of mental health problems and a lack of mental health services. There were high rates of emotional and behavioral problems among two sub-groups that could benefit from intervention: young children and children who remain in their family-of-origin homes. The authors suggested that counties and child welfare systems were missing opportunities for service delivery and that

improvement in this area may raise child mental health status, lessen repetitive family problems, and reduce the need for future child welfare interventions.

In studying access to mental health services within the child welfare service delivery system, Humphrey et al. (2006) interviewed 33 participants to gain their perspectives on changes in child welfare policy that reduced the amount of time allowed for families to correct child welfare problems. Participants were asked if the shorter time changed access to mental health services for families. Interviews were conducted with foster youth, primary caregivers, judges, foster care providers, and other service providers. Some participants viewed service providers as having less legal pressure to provide services because of the shortened time frame.

Summary. The above research informed on pathways for children to enter into service delivery systems and provided insight on studying access to educational and health care services as separate but interrelated pathways of the service delivery system for children with ADHD. In addition, the work recognized an important contribution made by the education pathway for access to mental health services in serving both as a point of entry (Farmer et al., 2003; Powell et al., 2007) and as a provider of services (Farmer et al., 2003). It also drew attention to the importance of service coordination among pathways (Burns et al., 2004; Farmer et al., 2003; Humphrey et al., 2006; Hurlburt et al., 2004; Inkelas & Halfon, 2002; Powell et al., 2007). There were problems reported in access to mental health services for children in the child welfare system (Burns et al., 2004; Humphrey et al., 2006; Hurlburt et al., 2004; Inkelas & Halfon, 2002) and recent policy changes were perceived by some study participants to further limit access to these services (Humphrey et al., 2006).

Conceptualization of Steps in Pathways

Conceptualization of access to services for the dissertation began by exploring the process of children entering into other service delivery systems through pathways. This conceptualization was further developed by recognizing service access steps commonly found within pathways as drawn from work by Powell et al. (2007) to include screening, identification, referral, and utilization. Service access steps in the education and health care pathways are considered to resemble these common steps from Powell et al., as described below for the health care pathway and described under the legal background section later on for the education pathway.

Steps in health care services pathway and related factors. The early work of Aday and Andersen (1974) described a behavioral model for health services use, providing a framework for studying issues in access to health care services (Andersen, 1995). According to Andersen (1995), the model suggested that health services use is related to three factors: (a) “predisposition” to use services, (b) “enablers” and barriers to care, and (c) “need” for care. The need factor reflects individual health status while predisposing and enabling factors occur at both individual and environmental levels. The model posits that these factors work together to affect access to care. This work from Aday and Andersen as well as Andersen informed the conceptualization of access to health care services for study in the dissertation. The impact of these three factors on service access was considered across the steps of screening, identification, referral, and utilization in order to gain a better understanding about the complex process for children to receive services as well as insights into why they may not receive services. For example, the predisposition factor might include being reluctant to use mental health services due to cultural beliefs that services will not provide remedies for the condition of ADHD, but the

need factor involves beliefs that the disability from ADHD is severe enough to require services. The enabling factor may be having private health insurance coverage that will pay for health care services. Using this framework to study access to health care services, factors that impact access were synthesized from the literature: cost and insurance factors, service supply and delivery system factors, and family and social factors.

Cost and insurance factors. Scholars have identified shortcomings in access to health care services related to cost and insurance factors for those with low incomes or without health insurance (Cheng, 2006; Studts, Stone, & Barber, 2006; Yu, Bellamy, Schwalberg, & Drum, 2001). Yu et al. (2001) used the Aday and Andersen (1974) behavioral model to study adolescents' access to medical and dental services. Predisposing variables for the adolescents included gender, age, race/ethnicity, birthplace, and language. Health insurance was included as an enabling variable, and self-perception of health status was employed as a need variable. Parent predisposing characteristics were age, race/ethnicity, birthplace, education, and marital status, and parental enabling variables included employment status and income. Study results showed that adolescents who lacked health insurance or who had low family income were less likely to use services. Adolescents not born in the United States were significantly more likely to lack lifetime dental care. Based on these findings, Yu et al. expressed concern that outreach efforts may need to be expanded in order to enroll more eligible children with immigrant status in the State Children's Health Insurance Program (SCHIP) in order to improve access to services for this group.

Cheng (2006) also used the behavioral model (Aday, 1993) and investigated factors affecting children's access to health care services within four different service areas: visiting a physician, visiting a dentist, using a prescription, and staying in a hospital. The study included

children enrolled in Medicaid or the State Children's Health Insurance Program (SCHIP). The enabling factors of family income and health insurance status had significant impact on access to services as reported below, but receiving Temporary Assistance to Needy Families (TANF) seemed to generally have little or no impact on service use except within minority groups, who were negatively affected for access to services when receiving TANF. Cheng reported children living in poverty were less likely than those not living in poverty to visit a physician, use a prescription, or stay in a hospital. Uninsured children were unlikely to use services. As the number of months a child received either public or private insurance increased, the child was more likely to visit a physician, visit a dentist, or use a prescription. The data suggested that many families found insurance unaffordable but also failed to enroll their children in public insurance. Cheng suggested that SCHIP helped with access to services for those with low incomes above the poverty level, while Medicaid supported those who were poor.

Studts et al. (2006) studied the determinants of problems in access to health care services for welfare recipients in one state. Using Andersen's (1995) behavioral model for exploring access to services, they examined predisposing factors for the characteristics of age, sex, race, marital status, and education level. None of the predisposing variables predicted problems in service access. The enabling factors studied by Studts et al. included having health insurance, type of welfare group (early leaver or time-exhausted), income, degree of food security, money worries, employment status, and location of residence by regions of the state. An important study finding was that the enabling factor of being without health insurance was the strongest predictor for participants having difficulty with access to health care services. For example, the odds of problems in access to services for both welfare groups (early leavers and time-exhausted) were four times as great for those lacking health insurance than for similar persons who had insurance.

The study also found that the enabling factors related to having money worries and being food insecure were important predictors of service access difficulties. In addition to the factors studied by Studts et al., study participants gave their own reasons for access to services problems in responding to open-ended questions. Some of the problems listed regarding lack of access to medical care were lacking money, not having health insurance, and needing services that were not covered.

In summary, having low incomes or being without health insurance have been found to negatively affect service access, (Cheng, 2006; Studts et al., 2006; Yu et al., 2001). Yet, families did not consistently enroll their children in public insurance programs for which they were eligible (Cheng, 2006; Yu et al., 2001). Predisposing factors restricting children's access to services included immigrant status (Yu et al., 2001) or being in minority group families receiving TANF (Cheng, 2006).

Cost and insurance factors in mental health services. Scholars have also studied financial factors (Gyamfi, 2004) and insurance factors (Pfefferle, 2007; Raghavan et al., 2006) related to mental health services use. Gyamfi (2004) studied a sample of children with serious emotional disturbances and reported service use differences based on family characteristics. Families living in poverty received fewer services despite having increased family mental health risk factors. Families living in poverty were also more likely to have older children, be non-white, be less educated, receive public assistance, and receive the support services of transportation and flexible funds. In a study by Pfefferle (2007), pediatricians reported insurance problems for children to access mental health services. These providers indicated that it was difficult for children to gain access to mental health services regardless the type of insurance used, Medicaid or private insurance, because insurance plans may limit the number of sessions allowed for

mental health services. The pediatricians in this study experienced the situation of a child falling back to their care for mental health services when the number of sessions allowed with a mental health specialty provider by a child's insurance plan was exhausted.

Work by Raghavan et al. (2006) examined insurance concerns for delivery of mental health services to children who were clients of the child welfare system. Selection of variables for study was guided by the behavioral model of access to services (Andersen & Davidson, 2001). The research hypothesized that children who were clients of the child welfare system would use ambulatory mental health services more and inpatient mental health care less in those counties that enroll child welfare participants into managed care plans that use behavioral carve-outs and that capitate mental health providers. Behavioral carve-outs refer to the practice of contracting mental health services separately from physical health services. No significant relationship was found between managed care and access to ambulatory services in this study. However, the authors did find lower odds of inpatient use for children served in carve-outs under Medicaid managed care. The authors noted that these findings suggested the need to be careful in adoption of carve-outs for this subpopulation. In particular, restricted use of inpatient services due to carve-outs may disproportionately affect children in the child welfare system, as they have high inpatient use rates.

Service supply and delivery system factors. Literature reported on the limited service supply available to provide children's mental health services (Pfefferle, 2007) as well as other system factors affecting their more general access to health care services (Cheng, 2006). The problems of service access specific to children with ADHD when services are required from both education and health care were also reported (Bussing, Zima, Gary, & Garvan, 2003; National Institutes of Health, 2000). The benefit of collaborative efforts among service providers toward

improved service access was recognized (Hodges, Nesman, & Hernandez, 1999; Tapper, Kleinman, & Nakashian, 1997; Papa, Rector, & Stone, 1998).

Pfefferle (2007) investigated the pediatrician point of view on access to mental health services for children. This qualitative study analyzed the responses of 90 participants to an open-ended question about factors that affect coordinating care. Overall, this group voiced concern about a lack of service supply in specific areas, including (a) the lack of mental health specialty providers, (b) frustrations with state mental health systems of care, and (c) their own struggles in trying to improve access to services. The short supply of mental health specialists and the great need for services led some general pediatricians to train themselves for treating children's mental health problems, to hire their own mental health staff, and to rely on telemedicine for psychiatric consults.

While a limited service supply may reduce service access, other factors such as the severity of need for care and having a previously established pathway to care may improve children's access to services. In reporting on need factors, Cheng (2006) found access to services mainly affected by children's health status and their prior service access. For example, those with poor or fair health were significantly more likely to use a prescription than healthier children. Visiting a physician was more than twice as likely for those with prior physician care as for those who had no prior physician care.

Some problems in service access specific to children with ADHD have been reported that involve both the educational and health care service pathways. One study found system barriers to be a common problem in service access, with parents indicating that they did not seek help because they did not understand where to begin seeking services (Bussing, Zima et al., 2003). Problems in access to services for children with ADHD that resulted from poor communication

between school personnel conducting educational assessments and health services personnel were reported at a 1998 conference on the diagnosis and treatment of ADHD (National Institutes of Health, 2000). Acknowledgement of this poor system coordination prompted the recommendation of a school based team approach that would include health care provider consultants in order to reduce this service barrier for these children.

A study on the implementation of the Children at Risk (CAR) program in Bridgeport, Connecticut, described some of the service delivery factors thought to be associated with its reported success (Tapper et al., 1997). This program was part of the national CAR project developed by the National Center on Addiction and Substance Abuse to prevent delinquency and drug use among high-risk youth in decaying inner-city communities. The CAR program used a school and community approach to deliver coordinated, comprehensive services to families with low incomes. It aimed to create multi-agency collaboration in communities by joining social, educational, and health services with those of the criminal justice system. Such collaboration was intended to allow a sharing of responsibility in approaching common goals with coordinated efforts. Formal agreements at the executive level and trust developed among those working at the program level were considered critical for the program's success. Weekly team meetings allowed the different sectors involved in community services to contribute and receive information toward an improved understanding of cases and an elimination of duplication in the collective efforts of providers. A trustworthy and supportive climate reportedly emerged across the disciplines responsible for implementing services. School administrators valued school-agency responses that allowed problems to be addressed as they occurred rather than waiting until they escalated. In work regarding another large program, Hodges et al. (1999) reported on the value of collaboration among providers delivering coordinated mental health services to children in the

“Systems of Care” federal program model. This program utilized a community approach to child mental health care.

The importance of developing and implementing specific training for professionals that enables them to gain formal coordinating and collaborating skills is opined in work by Papa et al. (1998). They considered such skills to be particularly vital in order to meet the rapidly developing health and educational needs of children, especially in regard to school-based health centers. Their discussion of this topic can be viewed as contributing to the development of more access friendly service delivery systems. Papa et al. emphasized how transforming a group of individuals from different professions into an effective collaborative team requires basic knowledge in areas such as communication skills and conflict management as well as practice in group work and decision making.

Family and social factors. The final factors discussed here are family and social factors. Outreach efforts and parent styles of service use affected access (Garbers, Tunstill, Allnock, & Akhurst, 2006). Parental expectations about child behavior affected decisions to seek care (Sayal, Goodman, & Ford, 2006). Stigma was reported as a barrier to accessing mental health services (Gonzalez, 2005) and other services (Gonzalez, 2005; Stuber & Schlesinger, 2006). Unmet service needs were recognized for children affected by language and cultural differences (Pfefferle, 2007) as well as other family and social factors (Cheng, 2006).

Cheng (2006) analyzed predisposing factors and provided a good overview for understanding a wide variety of demographic and socioeconomic factors such as age, gender, race, ethnicity, residence, and factors related to the socioeconomic status of the child’s mother. Cheng found a significantly higher chance of younger children visiting a physician or using a prescription when compared to older children, and girls were more likely than boys to use a

prescription. The longer a child lived in a metropolitan area, the greater the chance of visiting a physician. A mother's medical services use significantly and positively influenced her child's service use, and a college-educated mother significantly increased the likelihood of her child using a prescription or visiting a physician. Race/ethnicity also had significant impact on access. Children in minority groups were 50 - 77% less likely than white children to visit a physician, visit a dentist, or use a prescription. Children in minority groups of a TANF sub-sample used services less except for hospitalization, and this raised the concern that they were not using regular or preventive care (Cheng, 2006). Providers of mental health care have also reported the additional need to serve children with language barriers and to provide culture-based interventions for special groups (Pfefferle, 2007).

Stigma is included in the family and social factors group, as it has been reported to be a barrier for access to mental health services (Gonzalez, 2005) and to other services (Gonzalez, 2005; Stuber & Schlesinger, 2006). Gonzalez (2005) speculated on stigma issues as barriers to mental health service access for urban children of color and their families living in poverty. According to Gonzalez, they feel stigmatized because of their negative experiences with formal systems of care, institutional racism, and the lack of access to services by minorities. The author called for planning alternative mental health services for this group, with culturally specific models of intervention and the location of child mental health services in settings where these families usually congregate. Such settings may include "schools, community centers, churches, settlement houses, pediatric clinics, and recreational centers such as the local Y or the police athletic league" (Gonzalez, 2005, p. 252).

Stuber and Schlesinger (2006) explained how stigma can discourage people from enrolling in means-tested government programs even when they are eligible to receive the

services. They studied stigma in welfare and Medicaid programs and suggested that participants may have experienced negative consequences of stigma in two different ways. The stigma may be related to “individual self-identity issues,” or it may be related to an “anticipated negative treatment from others.” In both programs, Blacks reported higher levels of stigma than Whites. In addition, those reporting health problems in both programs reported more of the negative treatment type of stigma. There was greater stigma for welfare than for Medicaid recipients, and relocating enrollment for Medicaid away from the welfare office appeared to reduce Medicaid’s treatment stigma.

The final factor related to access discussed in the family and social factors group concerns parents. The diagnosis of ADHD in a child can bring forward many questions and concerns from parents about the well-being of their children. As with all disabilities, learning about the disorder and its problems is an important part of being able to seek effective services. In addition, each parent brings unique attributes to the help-seeking process, including potential challenges stemming from their own culture and background. Garbers, Tunstall, Allnock, and Akhurst (2006) reported on access to services as a continuum of system outreach efforts affected by parental styles. Their work drew on program evaluation data covering service delivery from 2000-2004 for a large national project in the United Kingdom, the Sure Start Local Programme (SSLP), and included detailed information about parental factors.

The evaluation data for SSLP included information from parents on how they learned about SSLP services and gained access to them (Garbers et al., 2006). The research emphasized how challenging outreach can be in that different families in the same community will have unique experiences, desires, needs for services, and socioeconomic characteristics. For example, a family who had a negative past experience in child protection referral might be cautious about

using other services. Other family problems found that might prevent their access to services included cultural barriers; literacy problems; mental health problems; parents under 20 years old; parents with substance abuse problems; and parents with learning disabilities, communication difficulties, chronic medical conditions, physical disabilities, mobility problems, or hearing or visual impairments.

The study on the SLLP project found that all parents did not engage equally in services despite the best quality of services (Garbers et al., 2006). The authors described the observed parent styles of service use as autonomous, facilitated, and conditional, explaining the importance of creative strategies to engage parents and families in every circumstance. The autonomous style parents take the initiative to access a service upon learning about it. Within the facilitated parenting style, while barriers to service use may be present, providing an advocate to help parents navigate the problems and encourage the initial use of services may be helpful. Finally, the conditional parents generally do not respond by seeking services when offered the level of support given to those parents in the facilitated category. This may be due to a variety of factors, such as requiring more intensive or more personalized services. They may still desire the benefits of services but require an alternative means of delivery such as receiving the services at home.

Although parent problems and different styles of service use by parents affected access to services (Garbers et al., 2006), other scholars reported that parental expectations about child behavior affect decisions to seek care (Sayal, Goodman, & Ford, 2006). According to researchers who studied parental involvement during the identification phase of help-seeking in the United Kingdom, it remains unclear if problems in access to health care services for children with ADHD occur even before their children's contact with a primary health care provider (Sayal et

al., 2006). Their study examined the contribution of parental views toward ADHD as it relates to seeking help and found child identification for ADHD to be dependent on parent recognition of child problems and on how severely those problems impacted the family. Although the United Kingdom's pathways to care differ from those of the United States, this work made an important contribution by calling attention to the role played by parental understanding of ADHD problems as it relates to seeking services for their children. This study as well as the other parent-centered research reported on emphasizes a parental component in service access that may present challenges for professionals in education and health care who interact with them. These challenges may be particularly relevant during the early stages of access to services, when parents may be unsure of the need for services.

Introduction of Systems Theory

The broad conceptualization of access to services through multiple pathways in service delivery systems (Powell et al., 2007) is used in this research to study access to services in education and health care for children with ADHD. The study is befitting macro level social work and is appropriately situated as deduced from the General System Theory that was first introduced by von Bertalanffy (1968). According to von Bertalanffy, conception of the biological organism, with organization as a whole or system, dates back to the 1920s and eventually led to the theory of open systems. The General System Theory focused on "the formulation and derivation of those principles which are valid for 'systems' in general" (von Bertalanffy, 1968, p. 32), defining concepts around organized complexity found in the biological, behavioral and social sciences. The author traced its rise to interest during the second half of the 20th century probably being from its contribution to a more suitable conceptual framework for both normal and abnormal psychology.

Janchill (1969) acknowledged the potential for general systems theory to bridge psychoanalytic theory and social science theory in intervention, as a way of thinking and analysis that offered a framework for understanding social interaction and the person-in-situation arrangement. Germain (1978) recognized general systems theory as a prevalent system of thought in social work practice. Later on, DeHoyos and Jensen (1985) credited the use of this “new theoretical approach” for moving social work practice from a medical model toward a more sociological model and emphasis on the individual’s social system (p. 490). They saw proponents of general systems theory as viewing individuals, families, larger groups, organizations, and nations as interacting within a larger system, in a context of communication, change, and growth.

Studies have reported on the benefit of using a variety of interventions in different service domains to serve children with ADHD (Coker & Thyer, 1990; Mueller, 1993) and on the value of systems theory for social workers who plan services for these children and their families (Bernier & Siegel, 1994; McCleary, 2002; Thomas & Corcoran, 2003; Yeschin, 2000). Tracing general systems theory back to von Bertalanffy, Andreae (1996) offered it as a paradigm for social work practice today where “changes can occur at any level of any system” (p. 613). The theory is applicable to this research that investigated access to services in separate but interrelated subsystems or pathways for children with ADHD. It was used in the dissertation as a lens to view the pathways of education and health care, both separately and as interrelated subsystems.

Summary of Conceptualization

Work by Powell et al. (2007) informed recognition of steps in screening, identification, referral, and utilization of services in the process of access to services through system pathways.

Insight from Aday and Andersen (1974) facilitated understanding these service access steps in health care, and legal background in the following section facilitates understanding these steps in education. This broad conceptualization of service access was operationalized in the dissertation by studying steps in the education and health care pathways of the service delivery system for children with ADHD. The dissertation work primarily involved studying access to educational services as supported by the legal background provided next and included examining complaints filed by parents in order to understand their problems of service access. The work also included focus group interviews with parents who attended support groups but did not file complaints, and these parents provided their perspectives on access to both educational and health care services for children with ADHD. Systems theory was introduced as a lens to view service access both within and across the two pathways studied.

Part Two: Background on Service Delivery System

Legal Background for Emergence of Services in Education

Both legislative and administrative actions have helped to develop policy that supports educational services for children with disabilities. Children with specific disabilities can be considered for eligibility to access educational services under federal legislation in two ways. The first involves using civil rights law, Section 504 of the Rehabilitation Act of 1973 (Section 504) (P.L. 93-112). The second involves using special education law, which began as the Education for all Handicapped Children Act of 1975 (P.L. 94-142).

Section 504. Section 504 prohibits discrimination on the basis of disability in programs and activities that receive federal financial assistance and provides some remedies in the event of violations. Under Section 504, protection is afforded to “any person who (i) has a physical or mental impairment which substantially limits one or more of such person’s major life activities,

(ii) has a record of such impairment, or (iii) is regarded as having such an impairment” [Section 504 at 29 U.S.C. §706(7)(B)]. Included in the list of major life activities is learning. Therefore, a child with a disability that substantially limits learning who attends a school that receives federal financial assistance can receive some educational service remedies in the form of accommodations and modifications.

A school district is required to have a designated team that acts under this law to make decisions regarding appropriate services for a child after the district has officially evaluated the child. The services offered to a student by that team are to be specified in a Section 504 Plan. Some examples of accommodations and modifications that can be used for students with ADHD are allowing classroom note-takers to assist the child, giving oral rather than written tests, teaching material in novel ways, teaching study and test-taking skills, and giving choices in assignments (DuPaul & Power, 2000). Kardon (1995) also suggested examples of modifications for children with ADHD, such as having them use a homework book to improve organizational skills and participating in a group that practices interaction skills.

If parents feel that their child with ADHD is being discriminated against due to a disability, they have the right to request that their child be evaluated in order to determine eligibility for receiving educational services under Section 504. They can do this by contacting the designated Section 504 representative at their child’s school. If the parents feel that the remedies provided under Section 504 are not made available to the child, despite their request, they can file a complaint with the federal Office for Civil Rights (OCR). The OCR investigates complaints of alleged discrimination thought to be related to a child’s disability.

Special education legislation. Special education policy for school children with disabilities was first initiated under the Education for all Handicapped Children Act of 1975

(P.L. 94-142) and has since developed through important revisions in the expansion of special education legislation. Braybrooke and Lindblom (1963) described a type of incremental social welfare policy: Non-repetitive change in policy development is viewed as a permanent but small policy change along a path that includes a sequence of policy changes. The development of special education policy that currently supports services to school children with disabilities was accomplished by expanding federal legislation from 1975 forward and can be considered representative of this type of incremental social welfare policy. The years of enactment for current special education law and former revisions that have the most relevance to this study are listed below.

- 1990, Individuals with Disabilities Education Act (IDEA) (P.L. 101-476)
- 1997, Individuals with Disabilities Education Act Amendments of 1997 (IDEA 97) (P.L. 105-17)
- 2004, Individuals with Disabilities Education Improvement Act of 2004 (P.L. 108-446)¹

An explanation of some of the legislative changes that are important to understanding this study follows.

Altshuler and Kopels (2003) explained that the purpose of the original federal legislation in 1975 was to provide a public school education for children who have disabilities, with many of these children having been denied this access to education in the past. They described how this important legislation mandated that special education be provided for children with disabilities in 11 categories but only if the disability adversely affected a child's educational performance. The 11 categories created were deafness-blindness, deafness, emotional disturbance, hearing impairment, mental retardation, multiple disability, orthopedic impairment,

¹ While this update in legislation is acknowledged, it is not discussed since it lacks relevance to the dissertation work of studying access to services related to the change in eligibility for children with ADHD under IDEA 97.

other health impairment (OHI), specific learning disability, speech/language impairment, and visual impairment/blindness. The authors discussed how disability eligibility has been expanded over time with new special education legislation. They explained that when the Act was reauthorized in 1990, IDEA added the two new disability categories of autism and traumatic brain injury. In 1997, special education legislative changes were again made. The new legislation and related regulations retained the basic rights and protections of children with disabilities and their families. According to Altshuler and Kopels, an important addition under IDEA 97 was that the definitions of two existing disability conditions were expanded: those for children with developmental delays and those for children with ADHD. The importance of this expansion for children with ADHD is elaborated below.

Disability of attention-deficit/hyperactivity disorder under IDEA 97. A federal administrative memorandum issued in 1991 (Office of Special Education and Rehabilitative Services) (OSERS) advised that children with ADHD could be considered for eligibility under the other health impairment disability category of the 1990 IDEA. However, children with ADHD did not gain formal entitlement to be considered for special education service eligibility specifically for their condition of ADHD until IDEA 97. Under IDEA 97, the other health impairment (OHI) disability classification definition was expanded to include children with ADHD if they met the new criteria. The language was changed to state the following:

Other health impairment means having limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—(i) Is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia,

nephritis, rheumatic fever, and sickle cell anemia; and (ii) Adversely affects a child's educational performance. [34 C.F.R. §300.7(c)(9)(i-ii)]

As with all disabilities, IDEA 97 did not mandate that every child with ADHD receive services. Rather, in order to receive special education and related services, it required that the child's disability of ADHD must adversely affect educational performance.

Understanding IDEA and IDEA 97 to help children with disabilities. In examining this part of the educational services delivery system, basic terminology and protections provided under IDEA and preserved through IDEA 97 are discussed first. One of the critical responsibilities for school districts is their role in "child find." This refers to the outreach process where children with disabilities who may be in need of special education are identified. School districts are required to follow up with an evaluation of these children, a thorough assessment in all suspected areas of disability. Those found to be eligible for special education and related services are then to be provided with a free appropriate public education (FAPE). The latter terms are formally defined, as follows:

The term 'free appropriate public education' means special education and related services that—(A) have been provided at public expense, under public supervision and direction, and without charge; (B) meet the standards of the State educational agency; (C) include an appropriate preschool, elementary, or secondary school education in the State involved; and (D) are provided in conformity with the individualized education program required under section 1414(d). [20 U.S.C. §1401(8)]

The term 'special education' means specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability, including—(A) instruction conducted in the classroom, in the home, in hospitals and institutions, and in other

settings; and (B) instruction in physical education. [20 U.S.C. §1401(25)]

The term ‘related services’ means transportation, and such developmental, corrective, and other supportive services (including speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disabling conditions in children. [20 U.S.C. §1401(22)]

Parents can request an evaluation for a child suspected to have a disability and thought to be in need of services. Once the evaluation is completed, then it is determined if the condition constitutes an eligible disability and requires special education and related services. If these services are required, a decision is also made regarding what type of placement is appropriate. Placement can be in regular, resource, or segregated special classrooms, or in a special school. The evaluation process requires the use of a variety of assessment tools, rather than relying on any one particular criterion. Any cultural factors that may influence the testing process must also be considered, and the assessment is to cover all areas of suspected disability.

Following an evaluation that finds a child to be in need of special education and related services, an individualized education program (IEP) is developed to address the unique needs of the child. The IEP consists of a written statement about the child’s present educational performance and planned goals as well as services required to achieve the goals within a specified timeframe, using measurement to assess achievement of the goals. “The term ‘individualized education program’ or ‘IEP’ means a written statement for each child with a

disability that is developed, reviewed, and revised in accordance with section 1414(d)” [20 U.S.C. §1401(11)].

School social workers advocate for children’s educational needs and have been recognized for providing professional services to children with disabilities since 1975 (Allen-Meares, Washington, & Welsh, 2000). As described by Altshuler and Kopels (2003), the role of school social workers was expanded under IDEA 97. It required a stronger school social worker role, through which social work services in schools include:

- (i) Preparing a social or developmental history on a child with a disability; (ii) Group and individual counseling with the child and family; (iii) Working in partnership with parents and others on those problems in a child’s living situation (home, school, and community) that affect the child’s adjustment in school; (iv) Mobilizing school and community resources to enable the child to learn as effectively as possible in his or her educational program; and (v) Assisting in developing positive behavioral intervention strategies. [34 C.F.R. §300.24(b)(13)]

Special education legislation and due process. Decisions about both offering special education services and selecting those services to be offered are to be made by a team knowledgeable about the child, with this team assembled according to the procedural requirements of special education legislative policy. Parents are an important part of the team process but have a right to due process when they feel that the school is not providing services appropriate for their child’s disability. Parents ask the school district for a hearing of their grievance in front of an impartial decision maker appointed by the state’s educational agency. This decision maker listens to the grievance and issues a decision. Due process hearings are state administrative proceedings, and either party is provided with the opportunity to appeal to a

higher level, which may include the courts.

Steps in education pathway. Steps similar to those drawn from Powell et al. (2007) are recognized in the process of access to educational services for children with ADHD. For example, the step of screening can be recognized in the child find responsibilities described for schools, and the step of identification can be recognized in the evaluation of children for eligibility. The step of referral can be recognized in the required team meeting to develop an individualized program for a child to receive educational services. The step of utilization can be recognized in parents using due process when they are dissatisfied with their children's educational services.

Comparing services received under Section 504 and IDEA or IDEA 97. Wright and Wright (2002) explained important distinctions between services received under the two legislative provisions, with stronger protections generally provided for children under special education legislation than under Section 504. For example, an independent educational evaluation at public expense is a right under special education legislative policy when parents disagree about the findings of the school's evaluation. This right does not exist under the policy of Section 504. Another difference involves educational benefits from the services offered. The focus of special education policy is on a program designed for the individual with educational benefits for the child, but Section 504 policy only grants the same opportunity to education for children with disabilities as it does to children without disabilities. Section 504 policy does not guarantee that a child with a disability will receive educational benefits from the education opportunity granted under the legislation.

In addition to providing educational services focused on the special learning needs of children with disabilities, school districts also provide mental health services for these children

including those with ADHD. Some mental health services may be provided in response to the needs identified and specified in a child's special education IEP, but other mental health services may be provided by schools in a more voluntary way. The next section describes a variety of service models used by schools to deliver mental health services, services that will sometimes be used by children with ADHD.

Background on Mental Health Services in Education

Children determined to be in need of mental health services will be impacted by the school's approach for delivering those services, and children with ADHD will sometimes use school mental health services. Three predominant models for delivering mental health services in schools are described by Massat, Ornstein, and Moses (2006). They described the traditional model as evolved from social casework with school social workers providing individual and group services for problems that interfere with learning and then generally making outside referrals for problems not involving performance at school. Problems reported by Massat et al. with this model include too few school social workers to serve the growing number of children in need of services. In addition, they explained children's needs for services at school may be recognized by social workers, but the social workers may not be allowed to serve the children's needs when the school considers the troubles to be of a nature that does not directly interfere with learning.

A second model is used by schools to deliver mental health services that partners schools with community agencies by contracting outside mental health professionals to the school site for help with children's longer-term and/or more intensive service needs (Massat et al., 2006). According to Massat et al. (2006), this model does make more services available on-site for students. However, the authors noted a disadvantage that workers from off-site are not as likely

to be well-informed about the unique issues faced by students at a particular school as the on-site school social workers.

The third model described by Massat et al. (2006) is the full-service school. They explained that schools using this arrangement may house many health services under one roof, including mental health services. Funding and confidentiality issues are some of the problems reported by Massat et al. with this model.

While some mental health services may be provided to children with disabilities through their schools under either special education legislation or voluntarily, there is no overriding health services legislation that guarantees their access to these services. While the government has a role in educating all children, and services to enhance education for children with disabilities have been legislated into practice, the government does not guarantee or legislate to require the delivery of mental health services to children outside of its focus on education. However, there is research to guide the delivery of mental health services to children with ADHD. That evidence base is reviewed in the next section.

Background on Evidence Base for Services in Health Care

The symptoms and problems of ADHD in children may cause parents to seek health care services for their children. A variety of professionals and treatments may be involved in attempting to meet such service needs. Unlike the education sector, there is no legal provision for health care services delivery. Nonetheless, as introduced in Chapter 1, the current recommendations for treatment of children with ADHD are widely available for review by health care practitioners. This section reports briefly on the evidence base from which the health care services pathway of the service delivery system for children with ADHD has developed, introducing background on psychosocial interventions in multimodal treatment plans.

Multimodal treatment plans. Early on, multimodal treatment plans were proposed for children with ADHD (Fell & Pierce, 1995; Gregg, 1995). Gregg (1995) discussed combining academic, behavioral, and medical interventions, with an emphasis on collaborative efforts and shared responsibilities among parents, health care professionals, and school personnel. Current recommendations for treatment include the use of medication for the symptoms of ADHD, appropriate school services, and educating parents on the disorder as well as providing parenting support (American Academy of Child and Adolescent Psychiatry, 2007).

Although the idea of using multimodal treatment plans persists, the components of individual plans may vary. Further, there is some disagreement about the appropriate use of psychosocial treatments for children with ADHD. Biederman and Faraone (2005) suggested that a clinician first successfully adjust medication treatment for a child with ADHD and then determine any remaining needs of the child in deciding about psychosocial intervention. Diller and Goldstein (2006) advocated for psychosocial treatment, arguing that although benefits derived from the treatment are difficult to measure in a quantitative way, most children with ADHD will be best served with combined psychosocial and medication intervention. In addition, there is a wide range of efficacy reported for psychosocial interventions. This section reports on work where a treatment was rigorously studied (Corcoran & Datallo, 2006; Jensen, 2001; McClellan & Werry, 2003; Pelham, Wheeler, & Chronis, 1998; Ralph, Oman, & Forney, 2001; Wells et al., 2006). It also draws on recommendations from experts in the area of ADHD (Barkley, 2002; DuPaul & Stoner, 2003).

There is empirical support for psychosocial treatment of children with ADHD that focuses on interventions with the parents. Ralph et al. (2001) evaluated a service model that used a combined treatment approach of medication and parent training to treat children with ADHD

from families with low incomes. Results supported the efficacy of the treatment model used with their study sample. Pelham et al. (1998) evaluated psychosocial interventions using predetermined criteria. They concluded that both behavioral parent training and behavioral interventions in the classroom meet criteria for well-established treatments while cognitive interventions do not. Parent-involved psychosocial interventions were also rigorously evaluated by Corcoran and Dattalo (2006), who conducted a meta-analysis of 16 studies. Their findings suggest parent involvement to be important for addressing the internalizing symptoms and academic problems of children with ADHD.

Using randomized controlled trials, McClellan and Werry (2003) determined the best supported psychopharmacology and psychotherapy treatments for child psychiatry. They reported that for ADHD there was some support for classroom interventions and parent training that involved contingency management and behavioral intervention strategies. Their findings support adding intensive behavioral interventions to treatment with medication for cases that are complicated or have co-existing diagnoses.

Longer-term outcomes of multimodal clinical interventions with these children have been rigorously studied in the National Institute of Mental Health (NIMH) Collaborative Multisite Multimodal Treatment Study of Children with Attention-Deficit/Hyperactivity Disorder (MTA) (Jensen, 2001). The MTA followed 579 children over 14 months. The MTA compared the relative successes of four types of treatment: medication management, behavioral treatment, combined medication management and behavioral treatment, or usual care approaches. The usual care approaches in treatment allowed the parent to choose services for the child from those services that were normally available in the community setting. The medication management and the combined medication and behavioral treatment showed significantly greater improvement for

core ADHD symptoms (problems of attention and/or hyperactivity-impulsivity) than the other two groups.

Other treatment impact studies using data from the MTA have been conducted, including a study that built knowledge about behavioral interventions with parents (Wells et al., 2006). In that study, baseline and post treatment observations of laboratory-based parent-child interactions were coded by observers unaware of the treatment condition. Child behaviors were not significantly affected by treatment type, but there were important findings reported for parent behaviors. The researchers found significantly greater improvements in constructive parenting for the combined treatment group than for the medication management or usual care approaches groups and suggest that interventions targeting change in parenting behavior may be important for these families.

According to the extensive literature review conducted by DuPaul and Stoner (2003), parent training services in behavior management strategies have been reported by several investigators to be an effective treatment approach. Yet DuPaul and Stoner expressed concern about the relatively small number of empirical studies and unanswered questions in this area. They called for more study of home-based behavioral family therapy for adolescents and view its development as potentially useful to address conduct problems and conflicts with family members. Such research would require determining which families may benefit from treatment and what specific service components to include. DuPaul and Stoner acknowledged the role of parent support groups in providing opportunities for parents to meet and exchange strategies, challenges, and successes. They noted that national parent organizations can provide information, opportunities to network, and strength in lobbying for support of services.

Barkley (2002) provided a brief overview to guide psychosocial treatments for use with

children who have ADHD. This overview was based on the compiled comprehensive literature reviews of three different sources. He emphasized maintaining treatments long-term for effective improvement in a child's prognosis. Barkley reported that behavior modification and academic interventions in the classroom, parent training in behavior management, and special education placement appear to have the greatest promise of efficacy. He recognized that other supplementary interventions may be necessary, such as coordinating multiple resources at school or problem-solving and communication skills through family therapies.

Study Rationale

Summarizing the need to study access to educational services. The processes through which educational remedies are obtained for children with ADHD have been explained in the background section. Before IDEA 97, children with ADHD may have received no services, received services under Section 504, received services under another category of disability under IDEA (Altshuler & Kopels, 2003), or received services based on the school's voluntary acceptance of the federal policy memorandum issued by OSERS in 1991 (Underwood & Kopels, 2004).

The new entitlement under IDEA 97 for children diagnosed with ADHD and suspected to need special education services to be considered for service eligibility under OHI would be expected to strengthen their access to these services. This raises questions about their access to services in special education under OHI since adoption of IDEA 97 as well as the nature of complaints filed surrounding IDEA 97 by parents when these services were denied. In addition, some children with ADHD reportedly obtained educational services through Section 504 before IDEA 97, but the extent that they were served through this route is unclear. Hearing from parents about their children's access to services under either of these educational service routes and

learning what service needs exist beyond the present delivery system would also be helpful in assessing access to educational services for children with ADHD. Little research has been conducted on this topic.

Summarizing the need to study parental perspectives on health care service access.

Regarding studying access to health care services, the focus of study for this project was not on examining specific health care models for treating ADHD, where diagnostic criteria and treatment recommendations for children are relatively well-developed and published. The niche of the dissertation was to report on the service access perspectives of parents engaged in health care services for their children with ADHD, an area that has not yet been well-studied.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

The emergence of services in education and health care that benefit children with attention-deficit/hyperactivity disorder (ADHD) was described in Chapter 2. In the education pathway, particular attention was given to the development of special education policy under the Individuals with Disabilities Education Act Amendments of 1997 (IDEA 97) (P.L. 105-17) that was expected to strengthen access to special education services for children with ADHD. Also in Chapter 2, the conceptualization of access to services for study in the dissertation was drawn from Powell et al. (2007) as access to services through pathways that include the common steps of screening, identification, referral, and utilization. In examining special education legislative policy, steps similar to these were noted in the education pathway of the service delivery system for children with ADHD, while similar steps were also noted in the health care services pathway by synthesizing factors related to service access rooted in an early model from Aday and Andersen (1974). With this conceptualization and the background on the service delivery system for children with ADHD, the study was designed to answer the research questions. Details are provided on its operationalization that used two methods under a social epidemiology approach: a legal method and a focus group method.

Social Epidemiology Approach

The research questions were answered using multiple methods and using a social epidemiology approach to study multifaceted issues of a topic that considers effects of social policy on health. According to Berkman (2000), a social epidemiology approach moves beyond examining traditional health care policy and toward understanding other policies that shape social organizations and social structures to impact public health. In the current study, special

education legislation was expected to have shaped school programs and services that help ameliorate the learning and psychosocial problems of a common mental health disorder in children that causes public health concern.

While this project's theoretical conceptualization was situated as deductive under the systems theory, its design and methods were consistent with a social epidemiology research approach. Syme (2000) explained social epidemiology in the context of traditional epidemiology, as follows. The purpose of epidemiology has been to prevent disease and promote health by studying the distribution of diseases in populations and attempting to identify the factors (determinants) that explain the distribution. Traditional epidemiology of infectious diseases determines the organism's route of transmission as water-, air-, food-, or vector-borne. Social epidemiologists do not have a comparable set of categories to study noninfectious diseases and conditions such as heart disease, cancer, injuries, mental illness, and suicide. Social epidemiology emphasizes that health and disease are influenced by factors at both the individual and group (or community) level, and it allows new ways to classify "disease," understand risk factors, and plan for interventions.

Syme (2000) contrasted the traditional sociology of medicine, wherein the attitudes and beliefs of patients in their sick role are of interest to those providing medical care, with a contemporary sociology in medicine (social epidemiology), or studying how social factors affect health and well-being. Scholars in social epidemiology identified important areas to study in research on health status and outcomes, such as socioeconomic inequalities, community and social relations, and social and economic policies (Berkman & Kawachi, 2000). Reminiscent of earlier work by the British scholar, Doyal (1981), Heymann (2000) affirmed that social and economic policies are central to improving population health and advocated for social

epidemiology research, seeing little hope of improving health without influencing policy. Berkman and Kawachi (2000) called for research that views the social distribution and determinants of disease in a community context, studying the associated factors under topics such as inequalities, neighborhood, community, work, and family. They saw this as a way to identify socioenvironmental exposures that may contribute to physical and mental health outcomes.

In this study, selected distributional features and related determinants (who had what problems, when, where, and why) were explored and described regarding access to educational and health care services for children with ADHD. This included describing ADHD complaints filed under legislation that supports educational services, using the chi square test of statistical significance to determine if the proportion of study complaints filed under special education legislation changed following the implementation of IDEA 97, and reporting on use of the other health impairment (OHI) disability classification during the last three years studied. In addition, parents engaged in the ADHD service delivery system for their children were queried in focus groups about access to both educational and health care services in this system. The intent was to learn more about access to educational services associated with educational policy and about parents' perspectives on service access in both pathways. The study examined the impact of IDEA 97 on educational services access for children with ADHD, identified common barriers to services, and reported on system strengths. The use of a social epidemiology research approach for the dissertation aligned well with the use of a deductive systems theory lens for viewing educational and health care services studied. The two methods used under the social epidemiology approach are now described, beginning with the legal method.

Legal Method

The legal method was used for studying access to educational services by examining complaints filed across the nation, mostly by parents and against schools. These complaints were filed under Section 504 of the Rehabilitation Act of 1973 (Section 504) (P.L. 93-112), under the Individuals with Disabilities Education Act (IDEA) (P.L. 101-476), or under IDEA 97 and were published during a 12-year period from 1992-2004. Data collected in an earlier project (Underwood & Kopels, 2004) was combined with new data collected in this dissertation research to create a new data set. This new data set allowed both longitudinal analysis of the complaints relative to IDEA 97 and reporting on the substantive nature of complaints for a sufficiently long period of time that strengths and weaknesses of this service pathway emerged.

Children with ADHD were able to receive special education services prior to IDEA 97 if they were eligible to be considered for services under one of the existing disability categories and were determined to need these services. As already explained, the other health impairment (OHI) disability classification was expanded under IDEA 97 to specifically include ADHD, and children with ADHD could be determined eligible for special education services because of their ADHD if an evaluation determined that it adversely affected their educational performance. This change arguably should have expanded their educational service access. Filing a complaint about educational services either with the Office for Civil Rights (OCR) or under special education legislation indicates that parents are dissatisfied enough with their children's educational services to take action against the school district. Some children with ADHD may not need these services, but others will need these services and should receive services. Studying complaints filed both before and after the implementation of IDEA 97 thus provided some important information about access to educational services for children with ADHD.

A legal method combined elements of legal research techniques and content analysis in order to study the complaints and learn about access to services in the education pathway. Mersky and Dunn (2002) explained that legal research is not reserved for law professionals and recognized that law impacts many social problems. They acknowledged that scholars outside of law can determine what legal information is desired and use available resources to aid in identifying, locating, and utilizing the appropriate legal materials. Morris, Sales, and Shuman (1997) drew a distinction between social science and legal research and explained that searching for the most recent information is more critical in legal research. They encouraged social science-related legal research. This social work research investigated complaints from a 12-year period of time during which a change in special education legislation occurred for children with ADHD. Study complaints were analyzed relative to early and later time periods that included approximately six years before and six years following the legislation, respectively. Stuart (2005) described using legislation in this way, as a historical research source.

A brief history of special education legislation was provided in Chapter 2, as background that gives important chronological meaning to the legal part of the study. With that background, the legal research questions were developed to study complaints filed under the administrative law system. Administrative law is “law that affects private parties, promulgated by government agencies other than courts or legislative bodies. These administrative agencies derive their power from legislative enactments and are subject to judicial review” (Shapiro, 2002, p. xv). The decision was made to use a legal research source known as a looseleaf service for studying the complaints, with steps then taken to locate, retrieve, review, and analyze the legal materials.

Looseleaf Services

At the time of the study's conceptualization, there was acknowledgement of the value of looseleaf services for use in legal research, given that law publishers traditionally strive to keep their materials current (Mersky & Dunn, 2002). According to Mersky and Dunn (2002), frequent updating requirements could be met using looseleaf services, "publications intended to provide timely and up-to-date access to legal information" (p. 265). The authors noted how looseleaf services used binders designed to allow a constant editing process, with pages that could be easily inserted or removed for speedy and accurate revisions that allowed systematic organization of the materials and use of a detailed indexing system for efficiency. Looseleaf services were particularly suitable for administrative law research and were available from a variety of publishers and in different focus areas (Mersky & Dunn, 2002).

Mersky and Dunn (2002) further explained that most looseleaf services consolidated relevant primary sources, secondary sources, current information, and other news into a single source. Primary and secondary legal sources have been defined, with primary authority defined as follows: "constitutions, statutes, administrative regulations issued pursuant to enabling legislation and case law. Primary authority may be either mandatory or persuasive. All other legal writings are secondary authority and are never binding on courts" (Shapiro, 2002, p. xxxii). Work by Jacobstein, Mersky, and Dunn (1998) differentiated primary from secondary sources, with a secondary source used to "explain, interpret, develop, locate, or update primary sources" (p. 10). They described legal research as a process through which legal researchers seek certain types of information using legal resource materials from primary and secondary sources, analyzing facts to reach conclusions and communicate those findings.

Data Source

Data were collected using complaints that were filed and subsequently reported in the Individuals with Disabilities Education Law Report (IDELR), considered the single most important reference tool in special education law (Individuals with Disabilities Education Law Report, 2001). The IDELR is a looseleaf service that contains decisions and rulings from federal and state courts, the U.S. Department of Education and its departments (including the Office for Civil Rights), state educational agencies, and due process hearing officers. It compiles and updates applicable federal statutes and regulations, reports cases, presents interpretations of policy, and is the only source to compile complaints otherwise unavailable for general access.

Complaint Sample and Data Collection

Decisions were made regarding which complaints to include in the data set by first examining all of the entries appearing under the Topical Index heading “Attention Deficit Disorders (ADD/ADHD)” in IDELR. A full-text review was completed for complaints that appeared to meet the study’s criteria for mild-to-moderate ADHD based on those entries. The complete data set of complaints entered into the study included 121 complaints that met the criteria from January 22, 1992 through January 21, 2004. This included entering into the data set the secondary data from Underwood & Kopels (2004) for the three years from 1998-2001 without any additional examination or review since their work used identical study criteria. The criteria for study inclusion were that children had a diagnosis or expected diagnosis of ADHD but seemed to be free of comorbidities such as conduct disorder or oppositional defiant disorder that might contribute to more severe behavioral or learning difficulties. Aggregated data on the route of access and the time period for the 121 study complaints is shown in Table 1 and includes sub-periods of time.

Table 1

Route of Access and Time Period for 121 Complaints Filed

Route of Access	Time Period				Total
	Period A (PA) 1/22/92 – 1/21/98		Period B (PB) 1/22/98 – 1/21/04		1/22/92 – 1/21/04
IDEA	31		36		67
	<u>PA1</u>	<u>PA2</u>	<u>PB1</u>	<u>PB2</u>	
	13	18	24	12	
Section 504	25		29		54
	<u>PA1</u>	<u>PA2</u>	<u>PB1</u>	<u>PB2</u>	
	12	13	23	6	
Total	56		65		121

Note. The three-year sub-periods of PA and PB are shown in chronological order.

Legal Analysis Objectives

The legal method allowed reporting on the complaints filed by parents who sought access to educational services for their children with mild-to-moderate ADHD under evolved legislation but had been dissatisfied enough with the services received to file complaints. The sample of 121 complaints included those complaints filed that were subsequently published in IDELR. There were four principal objectives of the legal analysis.

The first legal analysis objective was to use content analysis as described below, to read and code the sample of complaints for assignment to one of the five mutually exclusive

categories: eligibility for services, evaluation, change-of-placement, sufficiency of services, and other. The second step of analysis involved a more in-depth substantive analysis of the complaints by complaint category for the emergence of important issues related to educational services, as also described below. In addition, the category of other was analyzed for the emergence of new categories. Third, the legal analysis examined the use of OHI in later complaints that received services during the final three years of the study. The fourth step of legal analysis used the chi-square statistical test to determine if there was a statistically significant difference between the proportion of complaints filed under special education during different time periods or sub-periods of interest. Data summaries of the sample characteristics for the route of access and the time period are shown in Table 1 and were used to compute the chi-square statistic. The following paired periods or sub-periods of interest were examined: PA:PB, PA1:PB1, PA1:PB2, PA2:PB1, PA2:PB2, and PB1:PB2.

Content analysis and additional substantive analysis. Content analysis allows the investigator to define, code, and tally a unit of analysis in recorded communications to generate data that can be counted (LeCroy & Solomon, 2001). In this study, the unit of analysis in recorded communications was a complaint decision published in IDELR. Krippendorff (1980) emphasized how the use of content analysis has matured into a scientific method for investigating sociological and political issues, where making replicable and valid inferences from the data concerning the problem's context is possible. In this study, it allowed findings to be reported on an important social work topic, investigating access to educational services related to developments in special education legislation for children with ADHD from complaints filed mostly by parents dissatisfied with their children's educational services. As part of the legal

method, manifest content analysis was used for initial organization of the complaints into problem categories based on substantive complaint information.

After each of the complaints was read, it was assigned to one of five mutually exclusive categories of disputed issues in educational services: eligibility for services, evaluation, change-of-placement, sufficiency of services, and other. This allowed the complaints to be organized for more in-depth analysis of the substantive nature of complaints that followed. This latter type of content analysis differs from the manifest content analysis and is referred to as latent content analysis (Holsti, 1969). The first four of these categories were previously identified by Underwood and Kopels (2004), and the parameters they described for these categories follow.

Eligibility for services.

To receive services, a child has to be determined eligible. Eligibility under IDEA 97 requires having a disability that falls under one of 13 specified categories that adversely affects educational performance. Eligibility under Section 504 is available to a child with an impairment that substantially limits the child's ability to learn. Disputes arise between parents and school districts when either party, usually the parents, believes the child is eligible for services and the other party disagrees. (p. 226)

Evaluation.

Under IDEA 97, schools have a responsibility for "child find," the process of locating and identifying those children with disabilities in their district that may be in need of special education services. In determining which children are eligible for such services, a thorough assessment is required in all areas of disabilities related to the children's needs. Before providing special education services, schools shall fully evaluate a child with a

disability. Under Section 504, evaluation of a child with an impairment shall occur before an accommodation plan is provided and before placement is made. (p. 227)

Change-of-placement.

Under IDEA 97, a team including the parents and other individuals who are knowledgeable about the child and his or her disabilities must make placement decisions for the child. Absent certain emergency situations (such as guns or other weapons at school), no changes can be made to the child's placement without reconvening this multidisciplinary team. Section 504 also requires the action of a group charged with placement decisions for a child. (p. 228)

Sufficiency of services.

Under IDEA 97, schools provide special education and related services to eligible children with disabilities. Under Section 504, children who have impairments that substantially limit learning may receive accommodations and modifications at school. In this study, disputes between parents and schools occurred when they disagreed on the types of services required and whether the services provided were being implemented as specified in their children's written plans. (p. 229)

Another analogy of the common service access steps conceptualized from Powell et al. (2007) is made in the education pathway here, drawing from the above work on problem categories of educational service complaints (Underwood & Kopels, 2004). For example, the complaint problem categories of eligibility for services and evaluation relate to the service access steps of screening and identification. Change-of-placement can be related to the referral step, and sufficiency of services relates to the step of utilization.

For improved understanding of complaint problems, the educational service issues that emerged within each of the five complaint categories were also examined. Notes on important issues were made after reading each of the complaints. Reviewing the notes under each specific complaint category allowed some important educational service issues related to the categories to emerge and be reported on. Among the 121 complaints, specific complaints were then chosen as representative complaints to serve as good examples for presenting these issues in findings.

Focus Group Method

Using the focus group method, parents were interviewed who attended support groups for ADHD in their role parenting children with ADHD. The method allowed reporting parental perspectives on access to services in education and health care related to their children's ADHD. These groups were formed in one Midwestern state and the participants were different parents than those parents involved in the study complaints. The method was used to investigate how well parents understood and used Section 504 and IDEA 97 and to study how parents believed schools responded to their requests for educational services. In addition, this research method explored parents' perceptions of their knowledge about the disorder and what health care services they sought for their children with ADHD.

The focus group method complemented the legal method in several ways. While the legal method's strength was in allowing in-depth study of actual complaints filed about educational services across the nation during a 12-year period that included a change in special education policy, the focus groups allowed a breadth of direct inquiry with parents about ADHD services in education and health care for their children with ADHD. In addition, the design to conduct focus groups in one Midwestern state allowed a recruitment plan for focus groups to be implemented that deliberately included perspectives of parents with low incomes. The study design allowed

confidential reporting on the income status of the parents in the sample, therefore making it possible to discern the views of economically vulnerable parents in reporting on access to services.

According to Morgan (1998), the focus group is a small group of people that is brought together to formally explore a topic, allowing persons' perspectives to be heard on an issue with which they are familiar. He explained its value as a qualitative research method in allowing more interactive discussion than is thought to be likely through individual interviewing.

As used here, the method enabled an understanding of nuances and processes in access to services by allowing parental perceptions and experiences to be expressed and interactively discussed. These groups were intended to provide a richer understanding of access to educational and health care services for children with ADHD, including information concerning strategies used by parents to facilitate service access. The ideals of focus group theory and practice as presented by Stewart and Shamdasani (1990) guided development of this study's protocol and recommendations on systematic analysis (Krueger, 1998) improved the method's rigor.

Recruitment and Sample

Purposeful convenience sampling was used to recruit the focus groups. The original research plan targeted recruitment sites in communities containing a public school district that reported the majority of children to be living in families with low incomes. This determination was made using the School Report Card, which is publicly accessible on the Internet and includes socio-demographic and academic information for the state's school districts. It was first used in this project to select communities in which more than 50% of the students in a school district were reported to be living in families with low incomes. Various resources were then used to locate support groups in those same communities. This included using the Internet and

contacting sources, such as library, health, and school personnel, to obtain group contact and schedule information.

The original research plan was to conduct four to six focus groups at ADHD support groups in such low income communities. However, this objective had to be modified because support groups were not available in many of the targeted communities. The sampling criterion consequently were adjusted to locate focus groups in communities in which the percentage of children in families with low incomes reported for a public school was at or above the mean percentage reported for that state.

The Protocol for Contacting Group Leaders was approved by the Institutional Review Board (IRB) and followed. Plans were confirmed to recruit and interview participants from a support group after the leader agreed to have the group participate. Even with the revised sampling criterion for locating low-income communities, only four sites were secured for the study.

The support group leaders introduced the investigator and were available to help in the event of group dynamics problems or other unpredictable events. The investigator read the Opportunity to Participate in Research Paragraph that was approved by the IRB, which introduced the researcher and her project plans and then invited parents to participate. Parents who chose to participate were asked to remain after the support group meeting that evening, at which time their Informed Consent (Oral) was obtained by reading the Informed Consent to them and giving a copy to each participant. The Oral Informed Consent was also approved by the IRB.

Motivation to participate appeared high, and none of the parents that attended support group meetings on the scheduled nights declined to participate in the focus groups. Only one parent had to leave before a focus group had ended. However, there was low overall attendance

at support groups, and this was compensated for by returning to one of the groups a second time and returning to another of the groups on two separate occasions. When returning to the same site, the researcher talked to different parents than those who had already participated in the study.

The focus groups were conducted during 2004. Data were collected from 20 parents in seven focus groups at four different sites, with the number of participants as follows: Site 1 = 3; Site 2a = 2; Site 2b = 2; Site 2c = 3; Site 3 = 4; Site 4a = 4; and Site 4b = 2. The focus groups were located in two rural and two urban communities of one Midwestern state. The researcher had no known association with the parents in attendance, and participants received no monetary compensation for their involvement in the groups.

Aggregated data on selective characteristics for the sample of 20 parents are shown in Table 2. The sample included four men and 16 women who discussed 12 boys and eight girls with ADHD during the focus group interviews. In addition, there was some racial diversity among the parents as well as a range of educational levels they completed. All but one of the parents had completed high school and seven had graduated from college.

Table 2

Selective Characteristics of the Parent Sample

<u>Characteristic</u>	<u>Parents (n = 20)</u>
Race	
White	16
Other	4
Gender	
Male	4
Female	16
Child gender	
Male	12
Female	8
Education	
Primary	1
Secondary	12
College	7

The reader is reminded that the intent of locating focus groups in areas likely to generate participants with low incomes was to improve the chance that enough parents from these groups would participate in the study for it to include the perspectives of parents with low incomes. The 2003 federal poverty guidelines were used to determine those focus group participants with low incomes. This designation was based on their responses to questions about household family size and income (see items 5 and 6) on the Background Information form (Appendix A). Incomes of

up to 200% of these guidelines were considered to be low incomes. Their responses indicated that more than half of the parent participants would have been eligible for programs serving individuals with low incomes, so it is likely the perspectives of parents from lower economic backgrounds are represented in this work. No further analysis of economic data was planned.

Interviewing

The maximum enrollment for each focus group was deliberately set at eight, in order to encourage active discussion and still allow adequate interview coverage within the planned 60 to 90 minutes for completion. However, the maximum number of participants in any of the groups was 4. Participants first completed an anonymous Background Information form (Appendix A) at the beginning of the session, which took about five minutes. The form was used to allow some estimation of sample diversity and asked demographic as well as socioeconomic questions. There were also questions about child health history and service access experiences in education and health care. The specific questions about access to educational services were centered on the legal framework that supports services. Although the perspectives of parents were mainly studied through focus group interviews, these questions may have helped to ready participants for discussing the topic in the focus group interviews that followed their completion of the Background Information forms.

An Interview Guide (Appendix B) was developed by the investigator and used to conduct the focus group interviews. It contained questions about parental knowledge, efforts, and experiences regarding services in education and health care for their children with ADHD. This structure of the Interview Guide questions around each of these dimensions allowed study of the common access steps in pathways from Powell et al. (2007): screening, identification, referral,

and utilization of services. The focus group method allowed a broad exploration of service access, studied in both pathways, education and health care.

The focus group discussions were structured by the questions so that the investigator/interviewer could move through the planned content areas, but the questions were not necessarily read verbatim. The discussions were loosely structured to cover the important topics, while still allowing flexibility in accommodating participants' priorities. A few examples of questions in the guide follow, and the reader is referred to the guide itself. In the knowledge area, the guide asks parents how they think ADHD impacts their children's education. It asks parents about their understanding of laws pertaining to schools providing services. Regarding efforts, the guide asks parents if they have asked their children's primary doctor for a referral to additional medical or mental health care, or to educational services. It further asks if referrals were made when they were requested, and if referrals that were made then led them to obtain services. In the dimension of experiences, parents were asked to describe any educational services their children received at school as a result of being diagnosed with ADHD and the impact such services had on their children's academic progress and social adjustment.

In order to encourage a willingness to participate fully in the discussions, anonymity was promised beyond research personnel, and group members were asked to maintain the confidentiality of the sessions. Each of the focus groups was conducted immediately following a support group meeting except in one case when the group leader identified the meeting's agenda as the research study. Plans were to complete each of the focus group interviews during just one session, and this was accomplished for all groups.

Data Analysis

Interviews were audio-taped and participant responses were transcribed verbatim. Participants were told that direct quotes from the interview would not be used, with the intent of encouraging a richer level of responses. Selected participant responses were paraphrased in the findings in order to help illustrate important themes reported regarding access to services in the education and health care pathways.

The transcriptions were analyzed using a modified cut and paste thematic coding technique adapted from methodology for focus group data (Stewart & Shamdasani, 1990). This is consistent with an axial coding process for focus groups described by Krueger (1998). The investigator marked passages that conveyed concerns about access to services or success in this pursuit and then grouped passages that appeared to be similar under one heading. This technique allowed reporting on the emergence of prominent themes and important areas of concern within those themes as sub-themes. It was useful for identifying themes that parents reported on in both successful and problematic areas of service access but was not intended to document the frequency of any given service access issue.

Integration of Methods

The study's social epidemiology approach and its multiple methods design allowed data collection on access to services for children with ADHD in the two service pathways of education and health care, with emphasis on studying the influence of special education policy on access to educational services. The separate but complementary methods used for data collection in the education pathway answered separate research questions for more understanding of this area. Conceptualization of access to services for the dissertation supported this broad approach to studying common service access steps in this service pathway (Powell et

al., 2007) and included using a lens of deductive systems theory for analysis of findings both within and across two service pathways. Findings for each of the study questions are reported next, beginning with those studied using the legal method in the education pathway.

CHAPTER 4

STUDY FINDINGS

There are two sections for reporting the study findings in this chapter. The first section reports legal method findings from studying access to educational services for children with ADHD by examining the sample of 121 administrative case complaints filed under special education or civil rights legislation during a period of time that included special education policy development for ADHD. Studying children's access to educational services that help ameliorate problems stemming from ADHD during a period of time surrounding implementation of a policy change is consistent with a social epidemiology research approach that was introduced in the last Chapter, and these legal findings follow from that approach taken.

In this dissertation, a lens of deductive systems theory was used for viewing access to educational and health care services in these separate but interrelated pathways of the ADHD service delivery system for children. Use of this lens allowed reporting findings from studying service access broadly, as steps in service pathways drawn from Powell et al. (2007). The legal method collected data on service access in the education pathway, but focus groups allowed studying access to services in both pathways and across pathways. The second section of this chapter reports focus group findings.

Legal Method Findings

The complaints filed were studied to learn about access to services in the education pathway. Findings are reported first from content analysis used to begin studying the substantive nature of complaints by assigning each of the 121 complaints to one of the five complaint categories: eligibility for services, evaluation, change-of-placement, sufficiency of services, and other. These results are followed by findings from the in-depth analysis of complaints within

each of the complaint categories. The complaint categories were examined in order to learn more about the substantive nature of complaints, allowing important issues of the disputes to be revealed and identified. Complaints are described from which to develop these issues, with examples of complaints drawn from both routes of access: Section 504 of the Rehabilitation Act of 1973 (P.L. 93-112) (Section 504) and the Individuals with Disabilities Education Act (IDEA) (P.L. 101-476) or the Individuals with Disabilities Education Act Amendments of 1997 (IDEA 97) (P.L. 105-17).

The section on legal method findings also reports the results from examining use of the other health impairment (OHI) disability classification in study complaints from the final three years investigated. The legal method findings end by reporting the results of using a statistical test based on the chi-square distribution to examine changes in the filing routes of complaints relative to the implementation of IDEA 97. The chi-square test was used with aggregated data on the sample's access routes and time periods in order to examine for these changes during paired time periods and sub-periods of interest based on this important legislative development for children with ADHD.

Substantive Nature of Complaints

These findings report on the substantive nature of complaints, under the first research question: What was the substantive nature of study complaints, as described by problem categories and important service access issues within categories? The reader is reminded of the two parallel routes for access to services. These routes for the study period included legislation for children with eligible disabilities to receive special education services under IDEA or IDEA 97 and included civil rights legislation of Section 504 that prohibits schools from discriminating against children with disabilities. The reader is also reminded of the two major time periods of

interest for the complaints filed under special education legislation. These time periods included the six years before and the six years after IDEA 97 because this law was expected to have an impact on special education services for children with ADHD. The early time period included those complaints that were published in the *Individuals with Disabilities Education Law Report* (IDELR) from January 22, 1992, through January 21, 1998. The later time period included those complaints published in IDELR from January 22, 1998, through January 21, 2004. The terms “early complaint” or “later complaint,” as used here, refer to a complaint from the early or later time period, respectively.

Use of content analysis to begin substantive analysis. Content analysis was used to begin studying the substantive nature of complaints. This initial analysis assigned the complaints to categories and organized the complaints for the in-depth analysis that followed. A description of the complaint categories used as well as the rationale for using the categories in this content analysis were provided in the study methods. The content analysis categories are shown, along with the number of complaints that were assigned to each category: (a) eligibility for services, 26; (b) evaluation, 31; (c) change-of-placement, 27; (d) sufficiency of services, 28; and (e) other, 9.

Other complaints. There were nine complaints that could not be assigned to the problem areas of eligibility for services, evaluation, change-of-placement, and sufficiency of services based on the substantive nature of the complaint. These nine complaints were examined for the existence of any newly emerging major problem areas; none were identified. The nine complaints concerned communication problems between parents and school districts, time deadlines as procedural issues, or general discrimination investigations by the Office for Civil Rights (OCR) that were not for a specific child.

Findings from the in-depth analysis of complaints within the problem areas of eligibility for services, evaluation, change-of-placement, and sufficiency of services are reported next. Some of the important issues that were revealed in the complaints are identified and developed in the complaints described, according to the method that was explained in Chapter 3. The route of access is included for each complaint description, with the time period also provided for special education complaints.

Complaints about eligibility for services. The requirements for eligibility under Section 504 and under IDEA or IDEA 97 for children with ADHD were explained in Chapter 2, and their new entitlement to eligibility under OHI under IDEA 97 if they required services was also explained. When schools found children with ADHD ineligible for services under either civil rights legislation or special education legislation, parents had the right to disagree with those decisions. Parents filed complaints about eligibility with the OCR for problems with services under Section 504, and they filed due process complaints concerning problems with eligibility for special education and related services under IDEA or IDEA 97. Two important issues are identified for development from the 26 complaints about eligibility: Disagreements occurred about initial eligibility, but disagreements also occurred after services were received, about continued eligibility that involved either the route of access or the loss of eligibility. The development of these issues follows.

Disagreements about initial eligibility. The following complaints about eligibility provide examples of disagreements that occurred before children initially received services. The disagreements usually involved parents wanting their children to receive services and schools denying services because children were determined to be ineligible.

Section 504. Two complaints filed about eligibility under Section 504 are described to illustrate the above issue. In *Gwinnett County (GA) Sch. Dist.* (2000), the complainant alleged that the school district discriminated against the child due to the child's disability of ADHD when it found her ineligible for services under Section 504. This student had ADHD and a learning disability in math. An OCR investigation reviewed documents and interviewed both district staff and the complainant. The investigation found that the school district did evaluate the student to determine if her ADHD substantially limited learning. The OCR determined that the district found her ineligible for services under Section 504, but the district then failed to document what caused the Student Support Team (SST) to find her ineligible, as supported by the following statement:

The District states that the SST considered a Section 504 Plan for the student but determined that the student did not exhibit a substantial limitation in one or more major life activities, however, this determination was not documented according to the District's procedures. (*Gwinnett County (GA) Sch. Dist.*, 2000, at 489)

The OCR held for the district, in part. The OCR did not disagree with the district having found the student ineligible for services but did disagree with the district's failure to properly document why the student was ineligible. In a Resolution Agreement, the school district agreed to continue following its procedure for Section 504 eligibility considerations and to revise its form to facilitate documentation of the procedure. The district also agreed to remind appropriate district employees about following the procedure. The letter of notification sent by the OCR to the school district regarding resolution of the complaint explained the eligibility requirements for children with ADHD under Section 504, as follows:

Students with attention deficit disorder (ADD/ADHD) are not automatically protected under Section 504. Children must meet the Section 504 definition of disability to be protected under the regulation. Under the regulation implementing Section 504 at 34 C.F.R. Section 104.3(j) a “person with disabilities” is defined as any person who has, has a record of having, or is regarded as having a physical or mental impairment that substantially limits a major life activity, such as, learning. Thus, depending on the severity of their condition, children with ADD/ADHD may or may not fit within that definition. (*Gwinnett County (GA) Sch. Dist.*, 2000, at 489)

In *Pentucket (MA) Public Schools* (2001), the parents of a son who had ADHD and language processing disorder filed a complaint with the OCR alleging that the school district discriminated against the student due to his disabilities by not providing him with a behavior plan. Yet at the time that the complaint was filed, the district had not determined if the child was eligible to receive services. The OCR investigated the allegation, and the district voluntarily assured the OCR that it would take action as specified in the Resolution Agreement. This Agreement specified that “the District will convene a team meeting with persons knowledgeable about the Student’s disabilities, including the Complainant (Complainant) to consider whether the Student needs a behavioral plan to address his disabilities” (*Pentucket (MA) Public Schools*, 2001, at 144). If the team determined that the student was eligible to receive services under Section 504, those services provided were to include a behavior plan.

The OCR resolved each of the above complaints by considering if the school district met its obligation to determine if the child who had ADHD was eligible to receive educational services under Section 504 because the ADHD substantially limited the child’s ability to learn.

The schools completed, or were to complete, evaluations of the children in order to determine this and were to document the outcomes.

IDEA, early period. The next two complaints also illustrate eligibility disagreements between parents and schools before children received services, but these complaints were filed under IDEA or IDEA 97. An example of a complaint from each time period is provided. In the first complaint, a hearing officer found that a child with ADD and an auditory processing deficit was ineligible for services under IDEA, and the parent appealed the hearing officer's decision (*Board of Educ. of the East Syracuse-Minoa Cent. Sch. Dist.*, 1994). When this complaint was filed, there was no entitlement for children with ADHD to be considered for eligibility under OHI in determining if services were required under special education, but the state review officer (SRO) considered the child for eligibility under each of three disability classifications. The SRO applied the IDEA eligibility requirements for all children with disabilities to the child as follows:

The issue is not whether the child has a particular physical condition, but whether the child's educational performance is adversely impacted by such condition to the extent that he requires special education and/or related services, which is the criterion for classification under both the Federal and State regulatory definitions of a child with a disability (34 CFR 300.7; 8 NYCRR 200.1[mm]). Therefore, the fact that the child has an auditory processing deficit and ADD is not dispositive of the question should he be classified as a child with a disability for educational purposes. (*Board of Educ. of the East Syracuse-Minoa Cent. Sch. Dist.*, 1994, at 1029)

In the above quotation, the SRO emphasized that the child's condition did not necessarily require special education services. The child was considered for eligibility, and an evaluation was completed to determine if he had a disability which required services. The SRO considered the

child for eligibility under the disability classifications of learning disability, other health impaired, and multiply-disabled and found that the child was not eligible for services under any of these classifications. The SRO agreed with the hearing officer and dismissed the parent's appeal.

IDEA 97, later period. In *West Chester Area School District, v. Bruce and Suzanne C.* (2002), an appeals panel previously determined that the student who had ADHD was ineligible for services under IDEA 97 based on the student's passing grades, and the parents appealed. The court said that passing grades should not be used as the only criterion to determine the need for special education services and noted the discrepancies between the child's verbal intelligence quotient and some of his basic academic skills. The student also received extensive academic assistance from his mother. The court found that the student was eligible for services under OHI under IDEA 97.

Disagreements after services were received. Another important issue was revealed in complaints about eligibility: Disagreements occurred after children began to access educational services. Complaints are described that involved this issue in two different situations. There were situations involving parents who wanted their children found eligible to continue receiving services, and there were other situations involving parents who wanted the route of access for receiving services changed.

IDEA, early period. An early complaint that was filed under IDEA involved a disagreement between the parent and the school district after the child lost her eligibility for special education services (*Dothan City Bd. of Educ.*, 1993). The child with ADHD was previously eligible for services under IDEA as a child with a learning disability. She made significant progress at school and was retested to determine if she continued to need special

education services for a learning disability. The results of the testing indicated that she was no longer eligible for educational services under IDEA as a child with a learning disability based on the district's criterion used for discrepancy between ability and achievement. These results and her school records were used in deciding that she "did not need additional services" (*Dothan City Bd. Of Educ.*, 1993, at 653). The district's eligibility committee recommended a regular classroom placement for her. The parent filed a complaint with the OCR and alleged in the complaint that the testing was inappropriate. The OCR investigated and determined that the testing was appropriate. The parent then made claims to the Dothan City Board of Education regarding the student having dyslexia. The Board requested a due process hearing. Statements from the Decision and Rationale for the hearing of *Dothan City Bd. of Educ.* (1993) included the following:

It is also the finding of this Hearing Officer that the placements of Susan during her time as a student at schools operated by The Dothan City Board of Education have satisfied all requirements of Federal and State law. It is also the finding of this Hearing Officer that Susan is not currently entitled to special education services as she is not a handicapped child as defined by Federal and State statutes and their implementing regulations. Based upon the findings of the Hearing Officer, Susan should continue to be educated in the regular classroom without special services. (at 654)

The hearing officer found that the student was no longer eligible for services under IDEA and ruled that the Petitioner prevailed. In addition to disagreements about a child losing eligibility as was illustrated in the above complaint, there were also disagreements on the legislative route for receiving services. This situation occurred in the next two complaints described, and a complaint is included from each time period.

In *Dougherty County Bd. of Educ.* (1994), the parents questioned if the current route of access to services for their child with ADD was appropriate. Their son was receiving services under a Section 504 Plan in the form of expanded explanation on directions for his assignments, assessments for the purpose of determining his monthly progress, less confrontational disciplinary techniques to improve his behavior, and ready access to a school counselor. The parents “challenged the accuracy of his assessment and the adequacy of his services” (*Dougherty County Bd. Of Educ.*, 1994, at 822). They were seeking IDEA eligibility for him. The hearing officer found that the child was not eligible for IDEA services under the disability classification of emotionally behaviorally disturbed. She concluded that the school met its obligations under IDEA, as follows:

. . . there has been no violation of P.L. 94-142. Reginald was making progress in school and his behavior was not impinging on his educational progress. Reginald was repeatedly tested for special education services and it was determined that he did not meet criteria.

(*Dougherty County Bd. Of Educ.*, 1994, at 826)

The student had shown academic and behavioral progress under his Section 504 Plan and was to continue receiving those services.

IDEA 97, later period. Another complaint example of disagreements about the legislative route for accessing services involved a student with ADHD who moved from another state (*West Bend Sch. Dist.*, 2000). He enrolled in a school district where he had a Section 504 Plan for the school year in question, but his mother requested that this school district provide a private placement for him. There was no indication from her son’s records that she provided to the school district that he had ever been found eligible for special education services. The district refused her request and claimed that the student had not been evaluated for special education

service eligibility. The district wanted to evaluate the student and asked his mother's permission to do so. The student's mother would not consent to an evaluation for her son. She began due process because she wanted him to receive a private placement under IDEA 97 eligibility. In his Decision, the hearing officer stated that "[Mother] appears to have been proceeding upon the mistaken understanding that [Student] is eligible for special education and related services . . . simply because he has previously been diagnosed to have ADHD" (*West Bend Sch. Dist.*, 2000, at 521). The hearing officer for this later complaint reviewed federal regulations on eligibility under OHI for children with ADHD, as follows:

The federal regulation at 34 C.F.R. 300.7(a)(9) defining 0111 provides in part as follows:

"(9) *Other health impairment* means having limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—(i) Is due to chronic or acute health problems such as . . . attention deficit disorder or attention deficit hyperactivity disorder. . . . and (ii) Adversely affects a child's educational performance." (*West Bend Sch. Dist.*, 2000, at 521)

The hearing officer continued in his Decision, as follows:

A mere diagnosis of ADHD does not a "child with a disability" make. The ADHD must in addition cause limited alertness with respect to the educational environment that adversely affects the child's educational performance such that the child requires special education and related services. (*West Bend Sch. Dist.*, 2000, at 521).

He also explained that the appropriate time for such a due process hearing request from the parent would be either upon completing the evaluation or after developing an individualized education program (IEP). The hearing officer dismissed the parent's due process hearing request

as premature. The Background information provided for this complaint indicated that the parent gave her consent to evaluate the student after she filed for due process and that the evaluation was in progress.

Complaints about evaluation. There were 31 complaints assigned to the category of complaints about evaluation. The legal requirements for evaluating children regarding their need for educational services were explained in an earlier chapter and are summarized here. Under Section 504, schools must evaluate children with eligible disabilities that may substantially limit their ability to learn before beginning service provision for these children in the form of accommodations and modifications. Special education legislation requires that school districts locate and identify children suspected to have eligible disabilities and to require services. A district is required to fully evaluate a child in all areas of suspected disability before deciding what, if any, special education services to provide for the child.

The complaints about evaluation were examined in order to learn more about the issues underlying disagreements in this area of educational services. Two important issues are developed in these findings: School districts sometimes failed to evaluate children or delayed in evaluating children, and school districts sometimes conducted incomplete evaluations of children. Examples of complaints about evaluation involving these issues are described below.

Districts sometimes failed to evaluate or delayed in evaluating.

Section 504. In *Decatur (MI) Pub. Sch.* (1992), a school did not allow a child who had ADHD to participate in a school field trip. The parents filed a complaint with the OCR alleging that the school district discriminated against their son due to his disability. The OCR investigated and found that the school knew that the student had ADHD. The OCR also found that there was repeated past communication between the school and the child's parents regarding the student's

academic and behavior problems at school. The school district did not evaluate the student despite these alerts. The OCR investigation also brought forward information about why the district did not evaluate the student, as follows:

Staff did not refer the student for an evaluation because they believed the student was intelligent and could control his behavior when he chose to do so. In addition, staff believed the student did not have problems as long as he took medication prescribed for his ADHD and received extra help in the classroom. (*Decatur (MI) Pub. Sch.*, 1992, at 594)

The OCR learned that the child's academic and behavior problems occurred at school even if he took his medication prescribed for ADHD. The OCR investigation found that the school district's efforts to provide extra classroom help for the student reflected the district's knowledge of the student's educational problems. The OCR held that it was not known if the student had a disability requiring services due to the fact that he had not been evaluated for eligibility under Section 504 as a student with ADHD. Without knowing if he required services for a disability, a determination of the school's alleged discrimination against him by excluding him from the field trip could not be made, so an evaluation was required to determine his eligibility. The complaint was resolved by the district's agreement to evaluate the student.

Another Section 504 complaint involved failure of the school district to evaluate a student diagnosed with ADD (*Calcasieu Parish (LA) Pub. Sch. Sys.*, 1993). The parents sought an independent evaluation and filed a complaint with the OCR. The OCR investigated and found that a classroom teacher referred the student for an evaluation because the teacher had concerns both about the child's academic work and about the child's classroom behavior. Some of the teacher's concerns were reflected in a complaint passage, as follows:

low spelling grades, problems with attention skills, task completion, concentration, memory, speed/accuracy in copy work, failure to turn in homework, poor class preparation, staying off task, exhibiting disruptive behavior during class time, roaming around the room, and making disruptive noises. (*Calcasieu Parish (LA) Pub. Sch. Sys.*, 1993, at 763)

The investigation also found that several parent-teacher conferences were held to discuss the student's disruptive classroom behavior and the student's poor academic performance. The OCR learned that the parents requested an evaluation three separate times, twice verbally and finally in writing. The district did not evaluate the student despite these steps taken both by the teacher and by the parents. The investigation by the OCR determined that the school district violated Section 504 for failing to evaluate. The district's agreement with the OCR to voluntary corrective action brought the district into compliance with Section 504. Under this agreement the district would complete an evaluation of the student.

Early period, IDEA. In *Chicago Pub. Sch.* (1995), an early complaint about evaluation filed under IDEA, the parents were dissatisfied with the school for delaying the evaluation of their child who had ADHD. They had the child evaluated privately. The school district then conducted its own evaluation of the child and found that the child was eligible for special education due to a learning disability and ADD. The hearing officer found that the school district was at fault for not acting in a timely way to evaluate the child. The district was ordered to reimburse the parents for the costs of independent evaluations that the parents had paid for.

Districts sometimes conducted incomplete evaluations.

Early period, IDEA. The early IDEA complaint of *Chicago Pub. Sch.* (1995) just described also serves as an example for the issue concerning incomplete evaluation of a child by

a school district. The parents were dissatisfied because the district delayed in evaluating their child who had ADHD and because they considered the evaluation conducted by the district to be incomplete. The position taken by the parents was that the incomplete evaluation resulted in the school providing services to their child that did not meet the student's need for educational services. The hearing officer criticized the school district for its deficiencies in evaluating the child for ADHD and more generally for its lack of competence to evaluate children who have ADHD, as reflected in the following excerpt from the complaint:

In addition, the testimony of school personnel involved in the evaluation of S indicates a lack of understanding and skill regarding the evaluation of AD/HD. As a result of this lack of understanding and skill, school placed themselves in the position at the outset of not being able to substantially verify S's diagnostic profile. And again, the role of the outside evaluations in adequately evaluating S is further affirmed. (*Chicago Pub. Sch.*, 1995, at 1010)

The hearing officer found that the school district was at fault for not fully evaluating the child in order to determine the services required before delivering services that did not meet the child's educational service needs. The school district was ordered to conduct staff in-service training on ADHD. The district was also ordered to reimburse the parents for their out of pocket costs both for the child's independent evaluations and for the child's tutoring.

Later period, IDEA 97. A school district's incomplete evaluation of a child might have resulted in an IEP that was not focused on the child's current diagnosis. This was the situation for the child in *Montgomery County Public Schools Maryland State Educational Agency* (2003). A parent was dissatisfied with the evaluation done by the school district because the district considered the child's potential for developing Asperger's Syndrome in the future in order to

determine the educational service needs of the child at the present time. The parent sought an independent education evaluation (IEE) and requested a due process hearing to seek reimbursement from the school district for the cost of that evaluation. The administrative law judge for the hearing criticized the school district for not focusing the student's evaluation on the child's current diagnosis of ADHD, as follows:

The focus in an educational evaluation should be the present. The Child's IEP for the current school year will be shaped by what is in the educational evaluation. The evaluation needs to focus on the current school year, not on what may potentially be required in the future. (*Montgomery County Public Schools Maryland State Educational Agency*, 2003, at 239)

The judge ordered the district to reimburse the parent for the cost of the independent evaluation.

Complaints about change-of-placement. There were 27 complaints assigned to the change-of-placement category. The placement of children for educational services refers to the delivery of educational services along a continuum for those children who are found to be in need of services. The delivery of services can range from slight accommodations to intensive special education services delivered in a therapeutic day school. Under Section 504, students receive educational services as accommodations and/or modifications under a Section 504 Plan. Under IDEA, a child's placement must be in the least restrictive environment, and the services required are written in an Individualized Education Program (IEP). The IEP states educational goals for the child as well as provides descriptions of the ways and means to achieve these goals.

The analysis of complaints about placement revealed an important issue: Parents sometimes disagreed with school districts about service placements and unilaterally placed children in private schools but expected districts to pay for these private placements. Under

special education policy on unilateral placement, a school district is not likely to be held responsible for the cost of a private placement when the parent makes a unilateral decision to place a child in a private school if the district has met its responsibility to provide free appropriate public education (FAPE) for the child. However, a district can be held responsible for the cost of a private placement if the district did not provide FAPE for the child and if the private placement was both appropriate and of educational benefit to the child. The complaints described in the findings below were filed under IDEA and IDEA 97.

Parents sometimes unilaterally placed children in private schools but expected districts to pay costs.

Early period, IDEA. The parents of a child who had a learning disability and ADHD refused to place their child in the special education placement that the school district determined an appropriate placement (*Arnold v. Santa Monica-Malibu Unified Sch. Dist.*, 1995). Instead, the parents made the decision to keep their son in a regular classroom. The student regressed in academic, social, and emotional ways. The parents then unilaterally placed him in a private school for learning disabilities and requested tuition reimbursement for the private school from the school district. The parents were not reimbursed and requested a due process hearing. The hearing officer's decision favored the school district. On appeal, the court upheld the hearing officer's decision not to reimburse the parents because the student had been offered a free appropriate public education (FAPE) at the public school.

In *Western Wayne Sch. Dist.* (1997), the parents rejected their son's new IEP because it was similar to his previous IEP, and the school district admitted that he was not making educational progress under his previous IEP. The child had learning disabilities and ADHD. The parents placed their son in a private school and sought tuition reimbursement for the private

school from the district. The hearing officer found the disputed IEP to be appropriate and denied the requested reimbursement, but the parents appealed. The appeals panel officers disagreed with the hearing officer's decision and found that the disputed IEP did not offer the required FAPE. A quotation from the complaint indicated the student's lack of educational progress under the previous IEP: "The panel noted the student was doing no work in regular education during the previous year and was disruptive, yet the district failed to propose any way of rectifying these problems" (*Western Wayne Sch. Dist.*, 1997, at 867). The appeals panel officers also found that the private school was appropriate and that the child made educational progress there. The parents were reimbursed by the district for the tuition of the private school placement.

Later period, IDEA 97. In the next two complaints described, the school districts were also ordered to reimburse the parents for the tuition of private school placements. In *Board of Education of the City School District of the City of New York New York State Educational Agency* (2002), the petitioners sought reimbursement from the school district for their daughter's private school tuition. The parents made the decision to place her in a private school due to their dissatisfaction with the placement provided by the public school district. Their daughter had ADHD and was receiving special education services under OHI, but the program offered by the district placed their daughter with other students of a very different (lower) reading ability. A hearing officer denied their request for reimbursement and decided in favor of the school district. The parents appealed. The review officer reversed the hearing officer's decision, ordering that the cost of tuition for the private school year be paid to the petitioners. According to the complaint's summary, "The district failed to prove the appropriateness of its proposed placement. The parents justified their claim for reimbursement by demonstrating that the private

school program offered a program which met their child's needs" (*Board of Education of the City School District of the City of New York New York State Educational Agency*, 2002, at 1015).

In *Board of Education of the Arlington Central School District New York State Educational Agency* (2001), the parents of a child who had ADHD placed the child in a private school and received reimbursement from the public school district for the cost of the private placement. The child was to return to the district and receive services under OHI, but the parents requested additional reimbursement from the district for the continuation of the private placement. The hearing officer found that the district failed to provide FAPE, and the decision to order that the district reimburse the parents for the child's continued private school placement was made relative to the "stay put" provision of special education policy. With the stay put provision, a child stays in the last agreed upon special education placement until a decision has been reached regarding the complaint filed. The school district appealed the hearing officer's decision, but the state review officer explained that a district must comply with the procedural and substantive requirements for developing an appropriate IEP. The district had not complied. The review officer found that the district had not complied because it held the child's team meeting without a parent present. This was a procedural violation. The district also had not complied because it failed to prepare a transition program for the student. This was a violation of substantive nature. The state review officer dismissed the petitioner's appeal.

Complaints about sufficiency of services. There were 28 complaints assigned to the category of complaints about sufficiency. Under special education policy, the sufficiency of services refers to a school district providing the required free appropriate public education (FAPE) to a child, including implementing the services described in an IEP. The sufficiency of services concept includes providing services that are comprehensive enough to satisfy the

provision of FAPE, but it does not require that services be provided to maximize a child's educational experience. Under Section 504, the sufficiency of services refers to a school district providing accommodations and modifications under a child's Section 504 Plan. Two important issues are developed on the substantive nature of complaints about sufficiency. One of these issues concerned parents wanting their children to receive different services than the districts agreed to provide or to receive services with more breadth, depth, or frequency than the districts agreed to provide. For cases involving a second issue, parents were dissatisfied with the implementation of services specified in a child's IEP or with the implementation of services under a Section 504 Plan. These two issues are developed in the descriptions of complaints that follow.

Parents sought more or different services than districts agreed to provide.

Early period, IDEA. In *Austin Indep. Sch. Dist.* (1997), the parents of a child who had dyslexia and ADHD wanted additional educational services specified in their child's IEP. They requested taped texts, a home computer, math instruction, a physical education evaluation, compensatory occupational and speech therapy, and extended school year services. The parents also requested that a different reading program be used with their child. The hearing officer responded to the request from the parents that the district use a specific reading program for their child and explained about school choice regarding educational methodology for services, as follows:

Although IDEA assumes parents will actively participate in the development of the individual educational plan (IEP), parents are not entitled to specify a particular educational methodology; as long as the district is providing an educational benefit courts

will not second-guess professional educators as to the specific educational program.

(Austin Indep. Sch. Dist., 1997, at 882)

The hearing officer found that the school district provided FAPE.

Later period, IDEA 97. The parents in the next complaint also disagreed with the school district about the content of educational services specified in their child's IEP. In *Yarmouth School Department* (2001), a student diagnosed with ADD received special education services under OHI. The parents wanted the IEP to specify the use of a particular visualization and verbalization method, and the amount of individual instruction included in the IEP was disputed. The parents also sought compensatory education by requesting reimbursement from the district for a private program that the student attended over the summer. The hearing officer's decision favored the school district. The district followed procedures to develop an IEP and provided FAPE. The student received educational benefits.

Parents dissatisfied with implementation of services.

Section 504. The following Section 504 complaint about sufficiency provides an example of a complaint filed because the parent disagreed with how the school district implemented services for her child. In *Livingston (TX) Indep. Sch. Dist.* (1996), a parent alleged that the district failed to implement the behavior management plan for her son with ADHD. According to the OCR investigator, this plan included "concrete/positive reinforcements for positive behavior" and "appropriate remedial action for negative behavior" (*Livingston (TX) Indep. Sch. Dist.*, 1996, at 327). The parent also claimed that one of the student's teachers made an excessive number of referrals for conduct in order to remove the student from her class. The statements that follow from the complaint's Summary reported otherwise. "The student's teachers had properly referred and implemented remedial steps according to this plan, OCR determined. Moreover, teachers

had given the student an opportunity to correct his behavior before resorting to a referral on several occasions” (*Livingston (TX) Indep. Sch. Dist.*, 1996, at 327). The OCR determined that the school delivered the student’s behavior management plan in a satisfactory manner.

The next complaint description also provides an example of disagreement about service implementation. In *Lamar County (MS) Public School District Office for Civil Rights, Southern Division, Dallas (Mississippi)* (2003), a parent alleged that her son who had ADHD was discriminated against by the district due to his disability. The parent claimed that the district failed to implement the classroom accommodations specified in her son’s Section 504 Plan that were to include “a low noise environment, written outlines of class assignments, seating near the teacher, avoidance of distracting stimuli, repetition of instructions and extra time on assignments” (*Lamar County (MS) Public School District Office for Civil Rights, Southern Division, Dallas (Mississippi)*, 2003, at 1091). An investigation by the OCR disagreed with the parent claims and found that the school was implementing services consistent with the Plan, as follows:

The district provided the student with a low noise environment, written outlines of class assignments, seating near his teachers, extra time on assignments, and other aids and services as needed. Teachers also gave the student extra time for assignments, copies of lesson plans, and the option to repeat failed tests. (*Lamar County (MS) Public School District Office for Civil Rights, Southern Division, Dallas (Mississippi)*, 2003, at 1090)

Early period, IDEA. In *Jefferson County Bd. of Educ.* (1993), an early IDEA complaint about the sufficiency of services, a child who had ADHD was found eligible for special education under OHI and was later found eligible under Emotional Conflict. The parents wanted a behavior management plan implemented for their son. The possibility of using such a plan for

this student, if it was determined that he needed one in the classroom, was included in the student's IEP under Emotional Conflict. The student's classroom teacher worked with the student's OHI teacher to develop a modification checklist for the student. It was designed to help him attain his academic goals and the checklist incorporated many behavioral elements. The district maintained that the services did provide FAPE for the student. The parents did not consider the use of this checklist to be an appropriate implementation of a behavior management plan for their son and rejected his IEP. They filed for due process alleging that the school district denied their son FAPE. The hearing officer agreed with the district that FAPE was provided and explained that this disability case is not unique, as follows:

The unstated premise of these Petitioners' case—like so many others—is that an 'appropriate' program is one which is precisely designed and implemented to achieve the greatest degree of success possible. As desirable as such an objective may be in a philosophical sense, it simply is not—and should not be—the legal standard by which compliance with the law is measured. (*Jefferson County Bd. Of Educ.*, 1993, at 494)

Use of OHI

This section reports on findings for the second research question: Did children in later study complaints receive special education services for their ADHD under OHI under IDEA 97 during the final three years studied? Children diagnosed with ADHD became entitled under IDEA 97 to be considered for special education service eligibility in the OHI disability classification due to their ADHD if they met the criteria, including that the ADHD was found to adversely affect their educational performance. Their use of the OHI disability classification to receive special education services after IDEA 97 was examined in study complaints during the final three years of the later time period in order to determine if children with ADHD readily

accessed these services under OHI in those complaints. Those complaints were examined because any effect on the use of the OHI disability classification following the IDEA 97 entitlement was expected to have manifested by the second half of the later time period. There were seven study complaints that received services under IDEA 97 during the three-year period examined, and the seven complaints were assigned to the categories of eligibility for services, change-of-placement, and sufficiency of services. Findings on use of the OHI disability classification in each of these complaint categories are reported below.

Use of OHI in complaints about eligibility for services. The use of OHI for receiving ADHD services was found in each of the three study complaints about eligibility for which children were found eligible to receive services during the final three years of the study: *Cape Henlopen School District Delaware State Educational Agency*, (2001); *Manhattan Beach Unified School District California State Educational Agency*, (2002); and *West Chester Area School District, v. Bruce and Suzanne C.*, (2002).

Use of OHI in complaints about change-of-placement. The use of OHI for receiving ADHD services was found in both of the study complaints about change-of-placement for which children received services during the final three years of the study: *Board of Education of the Arlington Central School District New York State Educational Agency*, (2001), and *Board of Education of the City School District of the City of New York New York State Educational Agency*, (2002).

Use of OHI in complaints about sufficiency of services. The use of OHI for receiving ADHD services was found in both of the study complaints about the sufficiency of services for which children received services during the final three years of the study: *Board of Education of*

the Locust Valley Central School District New York State Educational Agency, (2002), and Yarmouth School Department, (2001).

Summary. During the final three years studied after IDEA 97, OHI was used in each of the seven study complaints for children with ADHD who had access to special education services for their ADHD. It was consistently used both for new eligibility and for continuing access to services.

Chi-Square Statistical Test

This section reports on findings for the third research question: During the period of time from 1992-2004, did the proportion of study complaints that were filed under special education change significantly with respect to the implementation of IDEA 97? The chi-square statistical test can be used to determine if the proportional changes for the variables being compared are statistically significant based on the expected and observed values (Montcalm & Royse, 2002). Parents filed administrative case complaints about their children's educational services both before and after IDEA 97 either under the Section 504 route of access (with the OCR) or under the special education route of access (due process of IDEA or IDEA 97). Answering this study question concerning significant changes in the proportion of complaints filed under special education during early and later time periods provides additional information for understanding effects of policy change on access to educational services in both routes of access for children with ADHD.

The chi-square test was applied to data on two characteristics of the complaint sample, access route and time period of interest. The aggregated data for these two characteristics of the complaint sample are shown in Table 1 for the 121 complaints studied during the 12-year period surrounding IDEA 97 legislation and includes sub-periods of time for the two time periods of

interest. These periods and sub-periods of time are as follows: Time Period A (PA), years 1-6; Time Period A1 (PA1), years 1-3; Time Period A2 (PA2), years 4-6; Time Period B (PB), years 7-12; Time Period B1 (PB1), years 7-9; and Time Period B2 (PB2), years 10-12. The pairs tested were formed from these periods and sub-periods of time. One degree of freedom was used, and the chi-square test statistic demonstrated no statistically significant difference in the proportion of complaints filed under special education between the pairs of time periods or sub-periods tested. The test results for χ^2 (with p values in parentheses) for the test pairs follow: PA:PB, 0(1.00); PA1:PB1, 0.39 (.53); PA1:PB2, 0.24 (.62); PA2:PB1, 0.03 (.87); PA2:PB2, 0.91 (.34); and PB1:PB2, 1.28 (.26).

Using the chi square test statistic to examine the time periods of interest and their sub-periods, there was no evidence of statistically significant change in the proportion of complaints filed under special education for the sample of 121 study complaints surrounding IDEA 97. Complaints continued to be filed both under Section 504 and under special education after IDEA 97. These results cannot be generalized to the broader collection of complaints filed for children with ADHD during the 12 years surrounding IDEA 97 because the representative nature of the sample in relation to this broader collection of complaints filed could not be determined.

Findings from Focus Group Interviews

The focus group findings are presented after studying the fourth research question: What did parents, especially those with low incomes, report about their understanding of ADHD and about their children's access to both educational and health care services for ADHD that help ameliorate its effects? Twenty parents who attended parent support groups because their children had ADHD participated in focus group interviews. The focus groups were held at four different sites in one Midwestern state. The parents answered questions about accessing both educational

services and health care services related to their children having ADHD. The aggregated descriptive data shown for the sample in Table 2 indicate some diversity in socio-demographic characteristics among the parent participants, but a majority of the parents had low incomes according to the study criteria.

Important service access themes that emerged from the focus group interviews are presented below and include thematic statements of findings. Paraphrasing and summarizing the participant response data were used to substantiate the themes in order to present the substance as well as to preserve the tone of the responses. The research design of obtaining oral consent from participants did not allow direct quotes from the interviews to be used in reporting the findings. The themes are organized for presentation under four sections: (a) knowledge of parents about the mental health condition of ADHD in children, (b) access to educational services, (c) efforts to access health care services and related experiences, and (d) service access themes across pathways.

Knowledge of Parents about the Mental Health Condition of ADHD in Children

Two themes are presented concerning the knowledge of parents on the mental health condition of ADHD in children: the knowledge of parents about the symptoms of ADHD in children, and the knowledge of parents about the problems of ADHD for children. Findings are reported below for these service access themes.

Knowledge about ADHD symptoms. Many parents were knowledgeable about the primary symptoms of ADHD in children, and they described their children's symptoms of inattention and/or hyperactivity. One parent recalled her frustration when she believed that her knowledge about ADHD was ignored by others. She told others about suspecting that her son had the disorder, and they doubted her suspicion. The parent kept questioning others, asking if

they thought that her son might have ADHD. The school nurse thought that the child had emotional problems due to family separation issues. Finally, a teacher told the parent that she was sure that the student did have ADHD. The parent called the child's physician who sent assessment forms for the teacher to complete on the child. The forms were returned to the physician, and the child was diagnosed with ADHD. In this case, it took persistence from the parent in order to convince others that she was right in thinking that her son did have ADHD. Her suspicion was based on the knowledge she had about the symptoms of the condition.

A different participant shared some of her early impressions related to seeing signs developing in her son that she began to recognize as the ADHD symptom of hyperactivity when he was only four years old. At that time, she already had experience with the condition of ADHD in her family. The parent said that this son was a very difficult child. She described him as having no fear. For example, someone could tell him not to touch a stove, and he would put his hand on it. He could be standing still and would say that he felt like he was moving at a very high speed. She could see that this was frightening for him. The parent talked about it being a challenge for her to get him fastened into his car seat.

Another parent had knowledge about the primary ADHD symptom of inattention and remembered a problematic situation at school for her daughter that was related to her daughter's inattentive nature. Her daughter was very well-behaved and was not hyperactive. The parent noticed that her daughter was unsuccessful in a first grade classroom incentive program. She questioned her daughter about why this was so, and her daughter was unable to offer an explanation. The parent questioned the teacher, who said that she was not sure if the child understood why she was unsuccessful in the incentive program. This caused the child's mother

even more concern because she believed that children usually did pay attention to and understand things like that.

In some cases, parents appeared to have been stimulated to learn about the condition following a child's diagnosis with ADHD. One child's parent summarized this quite simply by saying that she and her husband studied to learn as much as they could about ADHD after their daughter was diagnosed. Another child's parents reported that they had little knowledge about ADHD before their daughter was diagnosed, but that they used a variety of ways to learn more about it after the child's diagnosis. They did not receive much information from the child's physician, but they learned about ADHD in several ways, including through books and the Internet. They also learned from talking to others related to children who have ADHD. Most of their information came from a relative who was a teacher experienced in working with children with ADHD.

Knowledge about ADHD problems. Many parents were familiar with both the learning problems of ADHD for children and the social problems of ADHD for children, and they saw signs of these problems developing for their own children at home and at school. Participants made relatively few comments about the problems of ADHD observed for their children in the home, but problems with homework were not uncommon. It was difficult for their children to complete homework assignments within a reasonable period of time. This resulted in children spending an excessive amount of time on their homework in order to complete it. One participant said that it was not unusual for her daughter to spend six hours each night on her homework assignments and that this pattern began around the third grade. The parent negotiated with her daughter's teachers when the child reached middle school, and agreement was reached to have

her daughter's assignments prioritized as well as to have a two-hour limit for doing homework each night.

The problem of keeping a child's interest in academic enrichment activities at home was brought up by one parent. She said that having her son complete this type of work on a computer maintained his interest in the work, which helped him to do better work and to work more efficiently. The parent talked about using another learning technology item at home for her son's academic enrichment activities. She said that using novel teaching tools in alternative learning modes was very helpful in this type of work with him.

Little information was forthcoming from parents on the social problems at home for their children. One parent described the conflict that resulted between a younger child with ADHD and an older sibling. The parent said that the older brother in the family was always looking out for the younger sibling because he wanted to keep his little brother safe. The younger sibling resented his older brother's protective nature because he thought that his older brother was acting like a father to him, and this contributed to arguments between the two brothers.

Although parents made few comments about the problems at home related to their children's ADHD, they talked quite a bit about their children's school problems. They described both learning and social problems. One parent emphasized that ADHD impacted her child's education broadly and in every way. The problem of resisting in cooperating at school was mentioned for one child. Another child was said to be affected by his weak impulse control and by his inability to sit down and listen. The parent also said that this child had problems concentrating. Another parent said that her daughter's mind seemed to wander and that this hindered her daughter in class. She said that her daughter would get lost in the learning process

unless the girl received individual attention. She was described as a shy child who did not want to ask questions.

A father said that his son did not focus at school and that it was difficult for the child to stick with something in order to complete it. The boy would get frustrated and would jump around. He did not manage time well at school. Another child's parent said that her son was on occasion excluded from the classroom. He was put in the hallway or sent to the office because the teacher was unable to deal with his behavior. In another case, a parent became very concerned about her daughter's disappointment in receiving poor grades at school. Her daughter would know the material for a test but fail the test. Her daughter's friends received much better grades than her daughter. This really disappointed her daughter because she considered herself to be just as smart as her friends. The parent worried that her daughter's disappointment in receiving poor grades at school might cause her daughter to give up on school at that time.

Access to Educational Services

Three themes on access to educational services are presented from focus group data: (a) parents lacked knowledge about legislation that supports educational services for children who have disabilities, and they lacked understanding of eligibility requirements; (b) school districts sometimes neglected evaluation responsibilities; and (c) service utilization under both routes of access.

Parents lacked knowledge about legislation and understanding of eligibility. Parental knowledge regarding civil rights legislation and special education legislation that support access to educational services for children with ADHD varied considerably. Only a few participants reported having no knowledge about these laws. Most parents indicated that they had heard of these laws, but they appeared to be confused about eligibility and evaluation requirements as

well as how to begin the process of seeking educational services for their children with ADHD. Only a few parents seemed to be confident in these areas, but they also appeared to have had extensive educational service experience with their children and/or to have had professional experience related to these areas.

Participant responses provided information both on their efforts and on their experiences related to seeking educational service eligibility for their children with ADHD. Analysis of the data identified four different combinations of participant knowledge about the legislation and of the eligibility outcome for the child. The four combinations reported on are (a) little or no knowledge, did not receive services; (b) little or no knowledge, received services; (c) more than a little knowledge, did not receive services; and (d) more than a little knowledge, received services.

Little or no knowledge, did not receive services. In one combination of legislative knowledge and service eligibility, children did not receive services and participants had little knowledge about the laws or they had no knowledge about the laws. In one case of this parent-child combination, the parent appeared to be very frustrated. She spoke about her struggles pushing for her son to receive educational services, although she said that she did not know about the laws. She succeeded in having her son diagnosed with ADHD by his physician. He was treated with medication and with child counseling. Her son had repeated behavioral incidents at school and received school consequences that included a suspension. Yet, he did not receive educational services from the school district.

In another case, a parent said that she did not know about the laws and that she would like to find out about them. She asked if anyone in the support group could help her by providing

a resourceful person to contact in this regard. She wanted to talk to someone who would give her information on the school's responsibility for providing educational services to her son.

Little or no knowledge, received services. In a second combination of legislative knowledge and eligibility outcome, children received educational services despite the parents' lack of knowledge about the laws. A parent from a case with this combination explained that her daughter had both a learning disability and ADHD. The school district took the initiative to find the child eligible for receiving services under IDEA 97. The child's mother reported her daughter to be doing pretty well, which seemed to indicate a benefit from the special education services that the girl received.

More than a little knowledge, did not receive services. A third combination of parent knowledge about the laws and child eligibility outcome included parents who had more than a little knowledge about the laws, but their children did not receive services. A parent in a case with this combination tried a variety of services to help her son. She tried services from a child development center, after-school programs, and counseling. The parent asked the school repeatedly about receiving educational services for her son, and the school did eventually evaluate him. His eligibility was undetermined at the end of that school year, despite the parent's request earlier for information on her son's evaluation.

More than a little knowledge, received services. In the last combination, the participants had more than a little knowledge about the laws, and their children did receive services. The following responses are from three focus group participants who represented this combination. One participant spoke in some detail about trying to obtain school services for her daughter. Her daughter began receiving services at school on a voluntary basis, but in the seventh grade she began receiving services under Section 504. The parent reported that the school district had been

working well with them on a voluntary basis to meet her child's needs, and the parent hesitated to pursue eligibility under Section 504 for that reason. She recommended that children have a Section 504 Plan rather than a voluntary plan. The parent felt it was up to her to educate the district on the child's learning needs each year when her daughter was receiving voluntary services. The parent indicated that she had to ask the district for help instead of being able to build upon a plan from year to year. The parent stated that she took the initiative to obtain eligibility for her daughter under Section 504, and she said that the initiative was worth it. The parent pointed out that the district did not take the lead to find her daughter eligible for educational services. She added that the district never acted as if the Section 504 Plan was not an authoritative plan, as the district knew that she would enforce their compliance with the Plan. She also said that she did not pursue eligibility for her daughter under IDEA 97 because her philosophy was to use the least restrictive plan for services.

Another parent said that her child's IEP under IDEA 97 provided important protection. The parent called it her insurance, as the written service plan contained therein had to be provided for her daughter in the manner specified. She stated that her child might not have been found eligible for services without the action taken by a private child psychologist who provided services to her daughter. The parent explained that the school district evaluated her daughter and determined that her daughter was not eligible for services. The private child psychologist thought that the child did have an eligible disability, and that the disability caused the child to be in need of educational services. She told the parent this and went with the parent to the school in order to discuss the matter with the school district. The district then found the child eligible for services under IDEA 97.

The third parent spoke about problems in access to educational services under Section 504. She stated that schools do not always readily provide reasonable accommodations for children with ADHD and that people argue about what the word reasonable really means in this context. In this case, the child did receive services after the parent had him evaluated privately.

School districts sometimes neglected evaluation responsibilities. Parents appeared to be unsure of the legal requirements for school districts to evaluate children with ADHD suspected to be in need of educational services. However, parents were convinced that their children needed these services. Parents confronted school personnel and asked for help but thought that school districts lacked initiative in evaluating children for service eligibility. Consequently, they took their own steps when districts failed to provide evaluations, and some parents sought private evaluations.

The school districts often responded less favorably than expected when parents approached school personnel seeking educational services for their children with ADHD. One child's mother said that parents know their children best, and that they have a responsibility to defend their children's rights. She gave an example of the school district having facilitated the process in order for her son to receive eyeglasses when he had problems with his eyesight. Yet the school district did not readily evaluate him to determine if services were required when she thought he needed educational services for his ADHD problems. The parent also spoke about the importance of school districts evaluating children early on when they are suspected to need services, rather than waiting for parents to demand these evaluations from districts.

A grandmother and guardian of a girl wanted the child to be evaluated for educational services. The participant reported being told by the school district that she was out of order in

pressing for such. She said she was told to mind her own business, and the girl was not evaluated for services at that time.

In some cases, a school district did not conduct a child evaluation but instead suggested that parents seek services outside of the school district in order to have a child diagnosed or in order to begin counseling. Some parents took the step that the school district recommended and yet indicated that the district delayed in evaluating or else failed to evaluate the child for educational services. The parents of one child appeared to be unsure of the distinction between a medical diagnosis for ADHD and an evaluation at school for educational services. They reported that they asked school personnel if their daughter showed signs of ADHD at school. The school personnel agreed to watch her closely for signs of ADHD over a period of time and later notified the parents that there were signs of ADHD. The parents were advised to take their daughter to a physician, and the teacher sent a note to the physician about the child's fidgeting and concentration problems in the classroom. Even though this child then received a medical diagnosis of ADHD, the school district did not subsequently evaluate the girl for educational services.

Another child's kindergarten teacher was concerned that the student showed signs of ADHD and told the parents this. The parents sought services for their daughter outside of the educational system. She was diagnosed with ADHD and began treatment with medication. The child's mother said that her daughter had diagnostic testing done privately, but this parent did not know if it included an evaluation for educational services. The mother stated that to her knowledge the school district did not evaluate her daughter before providing services under IDEA 97.

One parent reported that the district did not evaluate her son and that he had a private evaluation. The district did utilize the private evaluation to determine that he was eligible to receive services under IDEA 97. This child had a history of behavioral problems at school prior to the time that he received the private evaluation. Yet the parent said that the school district neither suggested any interventions for her son nor showed any real concern for the child's behavior problems until after the private evaluation was done. She thought that the district knew that her son was quite intelligent and that this was the reason school district personnel did not consider that he might have ADHD. Another case involved the school district eventually evaluating a child after she received a private evaluation. The district provided services to her under IDEA 97 at the beginning of fourth grade.

Service utilization under both routes of access. Parents recognized the route of access under which their child received educational services or the voluntary nature of educational services received. They identified many different educational strategies and educational methods that their children received at school. Examples of voluntary services were given that included redirected behavior, brain stimulation activities, one-on-one sessions with staff, math and reading programs, and speech classes.

Parents gave examples of services that were provided as part of a child's IEP or Section 504 Plan. Some of these services involved homework or involved communication with parents. Examples from this area were written homework assignments, homework priority setting, daily homework time limits, extra sets of school textbooks kept at home, parent signatures in an assignment book, verbal progress reports, and written progress reports. Other IEP or Section 504 services related to time management or to organization. These included extra time for taking tests, advance notice on projects, study guides, resource time and resource rooms, skill building

on organization, use of a daily planner, and case manager services from a resource teacher. A final group of services that were implemented under an IEP or a Section 504 Plan involved expanded academic support and behavioral support. Among these were skill building in math, peer note borrowing, reduced spelling lists, dictating to typists, note takers, tests read aloud and questions clarified, summer school, books on tape, after-school study groups, reading programs, preferential seating, prompting, and class breaks.

Only a few parents reported more in-depth on their children's utilization of placement services or on the sufficiency of services. Among the few parents who did offer information specifically on the service utilization process, a parent from each of two different families spoke about working privately on a child's educational services plan before the child's IEP or Section 504 meeting was held. This work included preparing a list of services that the parent expected the school district to provide for the child. The list was used later on in discussion with the school district in meetings to develop the child's IEP or Section 504 Plan. One of these parents said that she also gave her list to others in the parent support group, in order to provide an example and to guide parents in preparing for similar meetings concerning their own children. She told parents about the importance of being proactive in making a list to request items for the service plan according to the individual child's needs. She explained that the school district can then respond to this list of items and that the district can add to the list. The parent thought that her daughter's need for educational services was met under a Section 504 Plan, and she spoke about her daughter doing well in the placement.

The other parent who spoke about preparing a list of services to request from the school also shared information on an aspect of services that she viewed as negative. This was related to her understanding that the purpose of her daughter receiving services under an IEP was to keep

the focus on educational benefit for the individual student. She said that the teachers used to tell her that her daughter was doing so well. The teachers compared the girl to the other students who were not doing so well. Those statements disturbed the parent, who said that her only concern was to know if her daughter's services under the school district's placement allowed her daughter to progress. The other students were not her concern, and she was not interested in having her daughter compared to them. The parent reported that she was happy with the services that her daughter received under IDEA 97.

One school district was described as having been more pressuring than helpful in a placement decision for a child who received voluntary educational services, which are educational services children receive outside of an IEP or a Section 504 Plan. In this case, the parents questioned the district's recommendation to place their child in specific classes for children needing improvement in the subjects of math and reading. The parents thought that the classes might not be the right placement for their daughter, as her knowledge of the subjects seemed to be appropriate for her grade level. They also thought that she knew the subjects, but that she was just too shy to demonstrate her knowledge of the subjects at school. They said that their child was not evaluated for service eligibility under IDEA 97 or Section 504, but that they felt pressured to agree with the district's placement of their daughter in the classes. The parents said that they thought their daughter did benefit from the reading program as her utilization of those services progressed.

The level of satisfaction with their children's educational services for ADHD problems varied among parents. Not surprisingly, parents seemed to be more satisfied when their children had access to services under Section 504 or under IDEA 97 and seemed to be less satisfied when their children received only voluntary services. Parents of the children who did not receive

educational services for ADHD problems expressed a variety of frustrations with school districts. They thought that their children needed educational services for these problems and wanted districts to provide these services.

Efforts to Access Health Care Services and Related Experiences

Data on parental efforts to access health care services and on their experiences related to those efforts were analyzed, and three themes are presented: (a) medication treatment responses varied, (b) insurance plans and parental concerns about medication costs, and (c) parents appeared to favor multimodal treatment.

Medication treatment responses varied. Parents were sometimes reluctant to have their children begin treatment with medication for ADHD, and the treatment responses for children varied. A few parents decided to have their children begin treatment with medication only after their own very careful considerations as well as consultations with providers. One parent spoke about her efforts in this regard, and she ultimately made the decision to have her daughter try medication for ADHD. She reported that she took her daughter's test scores from two different evaluations to the pediatrician. The evaluations were completed by two different psychologists. The parent said firmly that she also took along her own assessments of her daughter as well as teacher assessments. She talked seriously about her careful watch of her daughter's response to the medication during the first few months. She maintained close communication with her daughter's teacher in order to monitor the medication response so that any necessary medication adjustment could be made slowly. The parent reported that her daughter's response to the medication was positive, with noticeable improvement within a week. Her daughter's teacher also saw the improvement.

Other participants also spoke about their children who began treatment with medication for ADHD and had favorable responses, although medication changes were sometimes required for the children. One of the parents explained that her daughter started taking medication for ADHD when her daughter began taking three or four hours each night to complete her homework. She said that the medication seemed to work immediately, and that it was combined with the school services already in place for her daughter. Another child's mother said that her son made wonderful progress with help from his treatment with medication. He became an excellent student.

Parents also reported negative experiences for their children beginning treatment with medication for ADHD. Some of the participants spoke about their frustrations when the expected improvements in their children did not occur or when children had unacceptable side effects from the treatment with medication. One parent said that her son refused to take the medication for ADHD ever again because of the side effects that he experienced. Another parent reported that her daughter's primary care physician referred her daughter to a specialist for children who have ADHD because of the child's problems with medication. In another case, the parent remained optimistic about finding help for her son who had an unfavorable medication treatment response. She said that his doctor was still trying to help him and that the doctor referred him to a neurologist.

Insurance plans and parental concerns about medication costs. The findings are first reported on access to health care services using private health insurance plans. This is followed by the findings on access to health care services for children who used public assistance health insurance plans.

Private plans. Most of the participant comments on using private health insurance plans to access health care services were in regard to the limited coverage for the cost of the medication that was prescribed to treat a child's ADHD. Parents considered this limited coverage to be unfair. In one case, a parent acknowledged the medication cost to be a financial burden for the family. She said that her private health insurance plan covered the cost of her son's health care appointments for ADHD well, but that the insurance did not cover the cost of his medication prescribed for ADHD. The parent also said that the high cost of her son's medication and the limited insurance coverage for it helped her to understand why parents might decide against their children receiving treatment with medication for ADHD. The family paid just under \$100 monthly for her son's medication.

The above participant elaborated on her dilemma regarding the financial burden of her son's medication. She said that she thought about calling her insurance company to ask if it would be possible for her to use a wholesale website to purchase his medication at a reduced cost. The parent said that she was not particularly interested in purchasing his medication through a website and that she really did not want to do so, but she did want to do something to bring down her cost for the medication. She did want him to take the medication and sometimes asked her son's physician for free pharmaceutical samples of the medication during her son's health care appointments for ADHD. She stated that she was reluctant to ask for the samples too often, as she was concerned that the physician might view her as not valuing her child's medication enough to purchase it.

Another child's father spoke about paying for the child's medication to treat ADHD, and he considered the medication to be a necessary expense. His private health insurance plan included medication coverage but required a co-payment for the medication. The co-payment

cost had been \$20 monthly for his child's medication. The cost doubled when there was a change in the medication prescribed, as the new prescription was not a preferred medication under the private insurance plan. The father said that he was particularly unhappy about his co-payment for the medication because he already paid a high premium to purchase the private health insurance plan. He thought that the medication coverage of the insurance plan should be more comprehensive, as the premium to purchase the insurance was so expensive.

The parent in another case chose to pay more for a medication to treat ADHD in order to have her child fare better. She reported that the coverage for a particular generic medication under her private health insurance plan was less expensive for her than the medication her daughter took. However, her child did not do well on the generic medication. The parent thought that her insurance plan should cover more of the medication cost. She stated that it seemed unfair because families requested reimbursement for very few medical expenses related to ADHD. Most of the responses from parents about private health insurance plans concerned the cost of medication, but one parent did report that behavioral health care appointments were not covered as well as the medical care appointments were.

Public plans. There was mixed satisfaction among parents regarding service access for their children using public assistance health insurance plans. Parents reported variability in the coverage provided by such plans. For example, one parent was very pleased with her son's coverage under this type of insurance plan and reported that it covered most of his services. Yet, other participants stated that public plans did not always cover the cost of the ADHD medication, and they noticed inconsistencies in the medication benefits.

One parent felt quite frustrated in the lack of access to psychosocial services for her son under this type of plan. She found it difficult to locate a provider willing to accept the plan as

payment for child counseling services. The parent reported that she sought the counseling services for her son because the school required her to do so. Her experience in approaching the community mental health center for counseling services included being told that her child would not be seen if he was already taking medication for ADHD. She finally found a counselor because the child welfare agency that was working with her helped to locate one, and the agency paid for the services.

Another child was receiving health care services under a public insurance plan, but his mother was deeply concerned about her son continuing to be eligible because of expected changes in her household income. She explained that it was critical for her son to continue taking his medication for ADHD treatment and for him to have insurance coverage for its cost. She would have paid \$216 monthly for the medication without the insurance coverage. It was a stressful situation for her to be worried about her son possibly losing his health insurance.

The above participant described the personal circumstances surrounding her stressful situation. She was a student enrolled in a nursing program. Her fiancé was a truck driver, and he did not have access to affordable health insurance. She worried that his financial contribution to the household would cause her son to become ineligible for the public insurance plan. She spoke confidently about the situation being temporary until she would graduate and would get a job that included a health insurance benefit for her son. But in the meantime, the situation was very stressful for her. The parent recently learned about another public program to access health services for her son. Her fiancé's income was not considered in determining eligibility. She applied for the program, but she was told that a decision on her son's eligibility might take two to three months. Her son's pediatrician encouraged her to keep reapplying for the program even if her son was denied eligibility.

Parents appeared to favor multimodal treatment. Not all parents relied solely on medication for treatment of their children's ADHD in the health care services pathway. Some parents had an interest in a more comprehensive approach to treating ADHD in children, and quite a few children were involved in a multimodal treatment approach that included both treatment with medication and treatment with at least one other type of intervention. One parent noted that treatment has really changed through the years in this regard. She remembered when medication was the only option available to families for treating children's ADHD.

Children who were receiving health care services treatment for ADHD typically began receiving services from primary care physicians, but the children's services sometimes evolved to include care from a counselor, psychologist, child psychologist, or child psychiatrist. In some cases, the additional care was received because the parents took the lead in seeking a referral for behavioral health services. For example, one child's physician was willing to refer the parents and the child for these services, although they had not yet taken the step to access the additional services. In another case, a child's physician was also willing to make such a referral, but the parent said that she thought more about it and decided to wait a while.

Some parents were pleased with the multimodal health care services provided by their children's physicians. One parent in particular valued the comprehensive health services that her son's pediatrician provided to them. The pediatrician routinely provided limited behavioral health services during the child's regular appointments for ADHD. The pediatrician explained things to the child's mother and listened to her concerns, but he also talked to her son in order to gain the child's point of view. The pediatrician did not really suggest counseling but gave his own input. The parent said that some of his suggestions seemed silly, and they really did not work, but that other suggestions he made were helpful. The pediatrician used child assessment

forms to obtain teacher feedback on the child and considered the feedback in order to help him make decisions on adjusting the child's medication for ADHD. He also requested that the child's mother bring copies of her son's report cards to her son's health care appointments for ADHD.

In another case, the parent was very pleased with the health care services that her son received from his pediatrician. She reported that the health care provider worked well with the child's school to obtain feedback on the child. In addition, the parent explained that the pediatrician recently referred her son to a neurologist for specialized care. He was referred because the pediatrician was unable to find a medication that was effective for the child's ADHD without causing severe side effects.

The above responses suggested that the parents viewed a child's primary care physician as responsible for coordinating health care services and using a multimodal treatment approach. In contrast, another view was that the parent be responsible for coordinating the service needs and the physician's role should be limited to prescribing medication. For one parent holding this second viewpoint, the approach for her daughter included medication, behavior management at home, and school services. The parent believed that each of these made an important contribution, and that they should be used in combination. She said that this approach worked very well for her daughter and that her daughter became an honor roll student. The parent became angry when some years later a pediatrician suggested that perhaps the child did not need the medication for ADHD since the girl's grades were good. She became angry because the parent knew that a great deal of hard work had been required in using this combination plan through the years in order for her daughter to be successful.

Another child's parent emphasized that the combination of some simple educational services as well as treatment with medication proved beneficial for her child. Her child also

became an honor roll student. In this case, it was unclear from the parent's comments to what degree the physician participated in using a multimodal treatment approach.

In a few cases, parents appeared to be quite disappointed in their health care providers because there was too much emphasis placed on medication treatment and a lack of consideration for treatment of family dynamics or children's social adjustment related to the child's ADHD. For example, one father stated that his child's health care provider did not spend a whole lot of time talking with either the parents or the child. His son received health care services from a child psychiatrist. The parent estimated that more than three fourths of the time spent during an appointment with the psychiatrist was spent on discussing treatment with medication. The participant made reference to the provider wanting to get them in for the appointment, make medication decisions, and get them on their way. The parent obviously thought that something was lacking in health care services received from this provider, although he did not state that he wanted a multimodal treatment approach for his son. The provider did use an assessment form to obtain feedback from the child's teacher.

In another case, the parents appeared disappointed that medication was the only treatment provided by their child's primary care physician. They received little educational information about ADHD from him, but he did make some helpful recommendations. However, the child's mother thought that the recommendations were made more because she specifically asked for the help, rather than as the physician's normal protocol for providing services. As for the physician's recommendations, he told them about a popular parent training program, which the family acquired both in tape and in book format. He also indicated that they could be referred for treatment with a psychologist, and that they could attend a parent support group meeting for help. Their child was later referred to a physician specialist for children with ADHD, due to the

child's problems with the medication for ADHD. The specialist said that it would be good for the family to begin services with a child psychologist, but he told the child's mother that the referral for such would need to come from the child's primary care physician.

Service Access Themes across Pathways

In addition to the findings reported within each service pathway, overarching themes emerged that crossed the health care and educational services pathways. This final section reports on the most important of these themes: (a) good communication aided service utilization, (b) importance of emotional support, and (c) feelings of stigma.

Good communication aided service utilization. After services were established, good communication was reported to occur quite frequently both between parents and providers and among service providers. Parents recognized that such communication enhanced service access and reported their experiences in this regard. The use of one specific information gathering tool seemed particularly supportive of good communication. Participants spoke about the benefit of providers using child assessment forms to communicate, which facilitated the sharing of information on children's behaviors and academic progress. These forms were most commonly used by physicians to obtain feedback on the child both from teachers and from parents. Parents were grateful when the teachers willingly cooperated in completing the forms, as physicians used the information to adjust children's medication treatment plans. Parents usually took the forms to the teachers and returned them to the physicians, serving as a liaison between these service providers. One parent said that her child's physician used this method every month or two. She praised the physician for communicating so well with her child's school.

Participants more generally described their efforts to have good communication with teachers. One parent contacted the school whenever there was a medication change for her child.

She hoped that the school would in turn notify her anytime that there was a noticeable change at school in either the child's learning or the child's behavior. In another case, the child's teacher knew that something was wrong when the student displayed unusually sensitive behavior in the classroom. She told the child's mother about her observation. The parent discussed the behavior change with her son's physician, and the child's medication for ADHD was adjusted.

Another child's parent spoke about feeling reassured by the communication plan established with her child's classroom teacher. The parent and the teacher had an understanding whereby the parent felt free to call the teacher for weekly progress reports on the student. Alternatively, the teacher sometimes sent home a written weekly progress report for the student. The frequent communication aided this parent in monitoring her daughter.

In another case, communication between the parent and the teacher was important in regard to evaluating a child's ADHD medication treatment response. They agreed that the child responded favorably to the medication and thought that the medication dose needed to be increased slightly. They wanted to observe her medication response until the second semester before notifying her physician that the dose might need to be increased. This parent appeared to be particularly skilled in communicating effectively in order to help her daughter succeed at school. For example, she once had a sense that school personnel thought that there was too much parental pressure on her daughter to do well in school. She kept the focus on her daughter. She explained to them that providing services to reduce her daughter's stress level would help her daughter to achieve. She told school personnel that it would be helpful to clarify assignments for her daughter, as this would reduce stress for the student who became nervous when worried about having forgotten an assignment. Another area of effective communication for this parent was that she met frequently with school personnel, including at the end of every grading period.

At the end of a school year, she asked school personnel to tell her about things that had not worked for her daughter during that school year, and she also asked them to recommend educational strategies that should be tried with her daughter during the coming school year.

Importance of emotional support. Parents identified several sources of emotional support for problems related to their children's ADHD. They valued this support and received it from service providers, churches, and other parents. As already mentioned, quite a few parents spoke about having good communication with both educational and health care providers when their children were receiving services. This communication is likely to have sometimes also included emotional support in addition to the primary informational support that was discussed under the previous theme of communication. One child's parents spoke specifically about the important support that they received from members of their church, who recognized their daughter's special needs at church and helped by accommodating those needs. Further, the parents thought that members of their church understood the challenges of parenting children with ADHD.

A few participants spoke about support among parents in dealing with problems associated with their children's ADHD. Parents found it beneficial to attend ADHD support groups, where they not only gained support but education and information as well. One participant stated that the support group Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD) gave her both knowledge and information about ADHD. The group particularly taught her about the importance of routines to help manage children with ADHD. Another parent emphasized that parents who do not attend support groups do not realize that they are missing out on the benefit of talking to other parents who also have children with ADHD. She said that talking to parents at support groups gave one other choices

and ideas. She stated that the parent support group was also very helpful because she found out that she was not the only parent dealing with problems from children's ADHD. She recalled learning about the different types of ADHD at a CHADD meeting, which helped her to understand the type of ADHD that her son had and how to adjust to it.

Feelings of stigma. Although there were no specific interview questions developed that asked parents in focus groups about stigma related to children's ADHD, parents talked about it. They identified stigma associated with their children having ADHD, and they recognized the power of stigma to discourage service access. Parents sometimes brought up responsible solutions for problems of stigma. One participant described the situation of stigma at her child's neighborhood school. Children with ADHD went to the school nurse if they needed to be given their medication for ADHD. Other children noticed them going to see the nurse and knew the reason for their going. Children known to have ADHD were teased by other children at school. One parent in the group reported that her son said that going to the nurse to take his medication made him feel labeled, and he told her that he wanted to stop taking his medication for ADHD because he did not want to be labeled. Parents also mentioned a solution for the problem of children feeling stigma associated with taking medication for ADHD at school. Children could take a special type of medication for ADHD that remains effective for a longer period of time. This eliminated the need for some children to take ADHD medication at school.

A parent in another focus group recalled an experience that she thought helped to reduce her daughter's feelings of stigma associated with having ADHD. The girl was hesitant to begin treatment with medication for ADHD, as she thought that others would view her differently if she took the medication. The pharmacist who dispensed her prescription medication for ADHD then told her that he had also taken the medication when he was a child. The parent thought that

this had a very positive effect on her daughter because her daughter considered the pharmacist to be a respected professional. The parent also said that she gave her daughter a list of famous people who have disabilities, in the hope that this would help her daughter by reducing stigma associated with having a disability. She wanted her daughter empowered to accept her disability and to recognize opportunities for success.

The parents at a third focus group discussed the impact of stigma related to parents attending support groups. Three parents in the group mentioned the idea of organizing parent support groups at their children's schools. The idea initially appealed to them, but then they realized that it was probably not a good idea since attendance was likely to be limited by the stigma associated with children having ADHD. They thought that parents would choose not to attend because they would not want others to know that their children have ADHD. One of the participants in the group blamed a stereotyping society for the problem of stigma and added that most of the problem stems from a widespread lack of understanding regarding ADHD.

Summary of Focus Group Findings

In summary, many participants were knowledgeable about the mental health condition of ADHD in children. They knew symptoms and problems of the disorder and saw signs of the condition in their own children. In the education pathway, parents lacked knowledge about legislation supporting educational services for children with disabilities and did not understand eligibility requirements for children with ADHD. They appeared to be unsure of legal responsibilities for schools regarding evaluations, and some parents sought private evaluations for their children when schools neglected these responsibilities. Parents were aware of the voluntary nature or of the route of access used by their child to receive educational services and were informed on educational strategies and educational methods included in those services.

In reporting on health care services, parents described both positive and negative responses to treatment of their children with ADHD medication. They also described financial hardships for families in paying for this medication even with public or private health insurance plans. Quite a few parents seemed to prefer a multimodal treatment approach for their children's ADHD, and parents who reported on their experiences in this area were supportive of its use. However, a few parents appeared to be seeking this approach and to be dissatisfied with health care providers when it was not made available to them.

After services began, parents often established good communication with providers in both service pathways, and they facilitated providers' use of child assessment forms to improve service utilization. Parents acknowledged the importance of having a support system for facing problems of ADHD in their children. Participants identified stigma for children with ADHD and their families and discussed its negative effects on service access.

CHAPTER 5

DISCUSSION AND IMPLICATIONS

In the first part of this Chapter, a lens of systems theory is used to look within individual service pathways for interpreting and discussing findings from each method separately, beginning with legal findings and considering effects of policy implementation under IDEA 97 on access to special education services for children with ADHD. In the second part of the Chapter, use of a systems theory lens continues that also allows looking across pathways at study implications derived from an integration of findings from multiple methods. Service dissemination problems are examined in education, service gaps are examined in health care, strengths and weakness are examined across pathways, and recommendations are made toward improving the ADHD service delivery system. A consideration of study limitations and benefits follows, and ideas for future research stemming from this dissertation are suggested.

Part One: Interpretation and Discussion of Findings

Legal Method

One of the important legal findings was that both routes of access to educational services, under special education legislation and under civil rights legislation, were used at relatively constant rates for filing complaints during both the early and later time periods studied. A change in the proportion of complaints filed under special education legislation was expected following the Individuals with Disabilities Education Act Amendments of 1997 (IDEA 97) (P.L. 105-17). However, the chi square analysis showed no significant change in this respect. Yet, this finding draws attention to the importance of Section 504 of the Rehabilitation Act of 1973 (Section 504) (P.L. 93-112), civil rights legislation, in continuing to support educational services to children diagnosed with attention-deficit/hyperactivity disorder (ADHD). In addition to these findings on

the continued importance of both routes of access to educational services for children with ADHD, the four major categories of problem areas persisted in special education complaints during both early and later time periods: eligibility for services, evaluation, change-of-placement, and sufficiency of services.

Although the proportion of all study complaints that were filed under the special education legislative route of access was similar in both early and later time periods, other legal method findings are interpreted as lending support to the expectation that IDEA 97 enabled access to special education services for children with ADHD. Findings that lend support to this interpretation are discussed in three areas. These areas include (a) complaint decisions on eligibility for services, (b) complaint decisions on problem areas other than eligibility, and (c) consistent use of OHI classification following IDEA 97. The first two areas are discussed below from findings on the substantive nature of complaints.

Complaint decisions suggest IDEA 97 enabled access.

Decisions on eligibility for services. Parents who filed complaints under IDEA 97 were likely to have some knowledge about special education legislation because they were involved in due process. However, some parents apparently lacked understanding of eligibility requirements for children with ADHD. The new entitlement for eligibility consideration under IDEA 97 brought questions about eligibility from parents and school districts that resulted in the filing of complaints. This related complaint activity is expected to have benefitted both parties by expanding understanding of eligibility requirements, including responsibilities for districts to evaluate for eligibility when children with ADHD are suspected to be in need of special education services.

An important policy interpretation made by decision makers regarding eligibility for children with ADHD under IDEA 97 concerned the requirement for these children to have an eligible disability that adversely affected educational performance. In *West Chester Area School District, v. Bruce and Suzanne C.* (2002), the student with ADHD was found eligible for services under OHI after the school district previously determined that the student was not eligible for special education services. While the district may have originally misunderstood eligibility rules under IDEA 97 for children with ADHD, this later complaint illustrates that due process resolved the dispute on service eligibility in favor of the student. The complaint decision reinforced that a school district is responsible for fully considering if a child's disability due to ADHD adversely affects the child's educational performance to require special education services. As appeared to be the case in *West Chester*, other districts may have the misperception that children who have passing grades are not eligible for special education services. Districts may continue to need information and reminders that correct any misperceptions regarding current special education eligibility requirements for children with ADHD.

In another eligibility complaint described, the hearing officer's response acknowledged parental misperception about eligibility for services (*West Bend Sch. Dist.*, 2000). The hearing officer remarked how the parent seemed "to have been proceeding upon the mistaken understanding that [the student] is eligible for special education services . . . simply because he has previously been diagnosed to have ADHD" (*West Bend Sch. Dist.*, 2000, at 520). This parent apparently misunderstood requirements for eligibility, but an evaluation of the child was in progress to determine eligibility at the time that the decision maker acted on the complaint. This later complaint is unlikely to be an isolated case of parental misunderstanding about eligibility requirements for special education and related services applicable to children with ADHD.

Parents may misunderstand policy implementation under current special education legislation and think that a child diagnosed with ADHD will automatically receive special education services. These parents may continue to need explanations on special education service eligibility for their children with ADHD and guidance in this area.

The actions of parents in filing complaints under IDEA 97 about service eligibility for their children with ADHD helped to advance educational service eligibility rights for those children. The special education policy development of IDEA 97 gave children with ADHD new entitlement to be specifically considered for special education eligibility under OHI when they required services, and its implementation in due process decisions enabled them to receive services when services were required in the complaints studied. Policy implementation was evident in decisions for the above complaints filed under IDEA 97 concerning eligibility for children with ADHD, as decision makers interpreted special education policy that was previously not legally applicable in such a specific way to children with ADHD. The right to be legally considered for service eligibility based on ADHD that began for these children under IDEA 97 has been preserved in the most recent special education legislative development and is currently available under the Individuals with Disabilities Education Improvement Act of 2004.

Decisions on substantive issues other than eligibility. In addition to filing complaints for their children with ADHD about eligibility under IDEA 97, parents filed complaints about other problems in access to special education services. Decision makers responded by interpreting IDEA 97 legislative policy for these problem areas as well and resolved conflict between parents and schools in these complaints. This resulted in clarifying disputed problem areas beyond eligibility for these children. Examples are given below of other policy interpretations that were made and used in complaint decisions presented in the findings, and these decisions also helped

with implementation of policy under IDEA 97. The complaint examples below were taken from the problem categories of evaluation, change-of-placement, and sufficiency of services and lend additional support to the entitlement of IDEA 97 having enabled access to special education services for children with ADHD when services were required.

Evaluation. Prior to the entitlement of IDEA 97, school districts may have been unsure of their responsibilities for evaluating children with ADHD in order to determine if services were required. Other authorities may have expected districts to evaluate these children and to provide services for them under OHI, but it was not a federal special education legal requirement to do so. There was evidence that this type of expectation occurred in one of the early special education complaints described. In that complaint, the hearing officer affirmed the broad responsibilities expected of the school district to identify children with educational problems stemming from ADHD in the complaint excerpt that follows:

Testimony and records have reflected a reluctance on the part of school personnel to regard AD/HD as an ‘educational’ concern, but rather, to view AD/HD as a ‘medical’ and/or ‘clinical’ problem. Both the U. S. Department of Education Joint Policy memorandum (9-16-91) and the ISBE Memorandum #91-63M from Gail Lieberman (11-8-91) clearly established that ADD (AD/HD) is an educational concern which can, in turn, warrant identification and service under IDEA and/or Section 504. (*Chicago Pub. Sch.*, 1995, at 1010)

Policy development for ADHD under IDEA 97 required school districts to fully evaluate children with ADHD for special education services when they were suspected to be in need of these services due to their ADHD. There was evidence of this policy being implemented in the

description provided for a later evaluation complaint, *Montgomery County Public Schools Maryland State Educational Agency* (2003).

Change-of-placement. An important issue in complaints about placement concerned expectations of parents to be reimbursed by their school districts for their children's tuition at private schools after parents acted unilaterally to place their children at private schools. In study findings for these complaints, decision makers again interpreted and implemented special education legislative policy. In complaint decisions, they explained responsibilities for school districts and parents regarding placements for children in accordance with a free appropriate public education (FAPE), and they determined consequences for disregarding these responsibilities.

Parents in an early complaint were not reimbursed when they placed their child in a private school. They were not reimbursed because the school district met its obligation to provide FAPE with a placement that satisfied the child's need for special education services in the least restrictive environment (*Arnold v. Santa Monica-Malibu Unified Sch. Dist.*, 1995). The situation was different for a later complaint. In *Board of Education of the City School District of the City of New York New York State Educational Agency* (2002), the decision maker found that "the district failed to prove the appropriateness of its proposed placement" (at 1015) and that the private program chosen by the parents for their child appropriately met the child's educational service needs. In this case, the school district reimbursed the parents for the child's private school placement.

Sufficiency of services. The requirements for school districts to provide FAPE have already been explained, but parents may naturally expect a higher level of educational opportunity for their children even when special education services provided by school districts

meet legal responsibilities to provide FAPE. Children with ADHD are not guaranteed to receive all of the services that parents may desire for them. Conflict may arise when parental expectations regarding special education services for their children exceed the level of service provision legally required from school districts. In reaching a decision for an early complaint about the sufficiency of services (*Austin Indep. Sch. Dist.*, 1997), the hearing officer cited earlier complaints that inform this area as follows:

In defining FAPE, the U.S. Supreme Court held that disabled students are entitled to a reasonable educational benefit, consisting of ‘personalized instruction with sufficient services to permit the child to benefit educationally from that instruction.’ Disabled students are not entitled to have their educational potential ‘maximized.’ *Hendrick Hudson District Board of Educ. v. Rowley*, 458 U.S. 176 (1982). The Act does not require an ideal education or the best education available for a certain child. . . . The *Rowley* court noted that the main thrust of the Act is to provide equal access to education, and that no particular educational outcome is guaranteed by IDEA. See: *El Paso Ind. School Dist. v. Robert W.*, 22 IDELR 1129, 1132-1133 (W.D. Tex. 1995). (at 881)

In a later complaint about sufficiency of services, the outcome also favored the school district (*Yarmouth School Department*, 2001). Although the student with ADHD received special education services under OHI, the parents may have failed to understand the boundaries of service provision for special education. The decision maker found that the district provided FAPE.

Summary. The resolution of conflict between parents and school districts by decision makers was reported in findings on the substantive nature of complaints about eligibility for

services, evaluation, change-of-placement, and sufficiency of services. Their decisions were discussed as lending support to IDEA 97 having enabled access to special education services for children diagnosed with ADHD. While complaint outcomes sometimes favored parents more, in other cases the outcomes were more favorable to school districts. Nonetheless, decision makers relied on interpreting special education law and applying its policy. The above interpretation and discussion of findings on the substantive nature of complaints suggest that neither the parents nor the school districts always knew about special education law or its policy on educational services for children with ADHD and that both parents and districts sometimes neglected to follow this policy. However, decision makers interpreted and followed this legislative policy in order to resolve disputes on access to special education services in complaints filed for children with ADHD, advancing implementation of policy on special education services for children with ADHD under IDEA 97.

Use of OHI suggests IDEA 97 enabled access. The use of OHI for receiving services is discussed in the context of legal findings that lend support to service access having been enabled for children with ADHD under IDEA 97. The definition of OHI was specifically extended under IDEA 97 to include ADHD, and children diagnosed with ADHD could receive services when it was determined that the disorder adversely affected their educational performance. This allowed children who met these dual requirements for eligibility to legally receive special education and related services under OHI. Legal findings reported that children who received special education services for their learning problems related to ADHD in study complaints for the final three years investigated did, in fact, receive their services under OHI. This finding lends support to IDEA 97 having enabled these children to legally access special education services under OHI when they were found to be in need of special education services for their ADHD.

Focus Group Method

Access to educational services somewhat limited. Focus groups findings suggest that access to educational services was somewhat limited for the children with ADHD who were spoken about by their parents. Many parents knew problems of ADHD for their children at school but did not know about how to obtain access to services, and parents reported evaluation problems for their children. These key points suggest that service access was lacking and are examined further.

Parents knew ADHD problems but did not know ADHD service access. Many parents were knowledgeable both about ADHD learning problems for their children at school and about ADHD social problems for their children at school. This was reported in findings under the section on parental knowledge about symptoms and problems of the mental health condition of ADHD in children. Parents thought that their children needed services for ADHD problems at school, but many parents appeared to be unsure of steps for seeking help from school personnel regarding their children receiving educational services.

Parents were lacking in knowledge about legislation that supports the provision of educational services to children with ADHD and did not understand eligibility requirements under Section 504 of the Rehabilitation Act of 1973 (Section 504) (P.L. 93-112) or under IDEA 97. Findings regarding parents' lack of knowledge about legislation and eligibility are somewhat surprising because of benefits that would be expected from their attending those support groups from which focus groups were formed. Such expected benefits would include gaining knowledge about legislation that supports access to educational services for their children with ADHD as well as obtaining information and support from parents having experience with children's ADHD and its service delivery system. These findings may be partially explained by the

presence of support group newcomers in focus groups but also point to the likelihood that additional parents lack knowledge in this area.

Parents reported evaluation problems. Some school districts may have neglected legal responsibilities for evaluating children with ADHD who were suspected to be in need of services and determining their eligibility under IDEA 97. Parents reported several problems with evaluations for their children: delayed school evaluations, no school evaluations, or private evaluations sought. In some of these cases, parents reported that school districts delayed in evaluating for services toward determining educational services eligibility even though parents contacted schools to express concerns about their children's educational service needs. In other cases, children who experienced evaluation problems with school districts were never evaluated by districts.

Among those children who experienced problems with school district evaluations, some did receive educational services after parents obtained private evaluations for them because parents took the initiative to seek these evaluations for their children. Further, since parents reported lacking knowledge of legislation supporting educational services, their abilities to challenge schools when evaluation problems presented were likely to be compromised. Therefore, focus group findings suggest that there was less access to educational services than expected for children with ADHD under legislation that supported these services, Section 504 and IDEA 97.

Parents reasonably satisfied with access to health care services. Participants in focus groups appeared reasonably satisfied with their children's access to health care services related to ADHD, except for two problems: personal paying for medication despite having insurance coverage and occasional complaints about providers who may have been lacking in a multimodal

treatment approach that parents seemed to desire. Findings for the health care services pathway are discussed here as informed by the synthesis of factors related to health services access in Chapter 2, largely from work that used the behavioral model for health services developed by Aday & Andersen (1974). The model is used in order to help explain why access to health care services may be more or less successful due to the influence of predisposing, enabling, and need factors (Andersen, 1995). The factor groups synthesized from the literature were (a) cost and insurance factors, (b) service supply and delivery system factors, and (c) family and social factors. The focus group findings were presented as themes and are discussed here for the themes of insurance, cost of medication, multimodal treatment, and stigma. Although stigma was reported in both pathways, it is situated here for discussion under health care services since the problem originates from the mental health diagnosis of ADHD in children.

Cost and insurance factors.

Insurance. According to economic and demographic data provided by their parents, the majority of children who were reported on in focus groups were likely to have qualified for public assistance health insurance plans with low income eligibility requirements. Most parents stated during these groups that their children were covered by a health insurance plan, but they did not always describe the type of plan as public or private. Some children were reported to be insured under public assistance health insurance plans. Even though background information indicated that the majority of children reported on by their parents in focus groups lived in families with low incomes, these children did not appear to be without health insurance. Having this insurance is expected to have favored their access to health care. Studies have found that families do not consistently enroll their children in health insurance programs for which they are eligible based on having low incomes (Cheng, 2006; Yu et al., 2001) and that being without

health insurance negatively affects access to health care services (Cheng, 2006; Studts et al., 2006; Yu et al., 2001). Although lacking health insurance was expected to be a common problem for the children spoken about in focus groups because the majority of participants reported having low incomes, responses from parents in focus groups indicated their children were generally covered by health insurance. However, parents did readily identify a different problem area under the service access factor group of cost and insurance. They talked quite a bit about the cost of medication, as discussed below.

Cost of medication. Parents talked about their financial frustrations related to paying for medication to treat their children's ADHD. They explained that health insurance plans did not always cover the total cost of this medication, or plans covered the particular medication that parents preferred for their children in a less comprehensive way than another medication. As was presented in the findings, one parent spoke at length and sincerely about the burden of cost for her son's medication to treat ADHD even though she did not seem to consider her family to be poor. As a result of her own experience paying for her son's medication, she stated that she now understands why some parents would choose not to use medication for treating their children's ADHD because of its cost. The cost of medication borne by parents to treat their children's ADHD is considered to have negatively affected access to health care services, and particularly so because the majority of parents reported having low incomes. Research has reported that having a low income (Cheng, 2006; Yu et al., 2001) or money worries (Studts et al., 2006) negatively affects access to services.

Service supply and delivery system factors.

Multimodal treatment. Many parents reported on their children using medication for treating ADHD. This implies that these children were already receiving health care services,

which is expected to have supported their continued access to health care services. Having previously established a pathway to health care services has been reported to improve a child's continued access to health care services (Cheng, 2006). This tendency for continued access to health care services is next considered in the context of expanded access to health care services sought by some parents who were interested in using a multimodal treatment approach for their children's ADHD.

Some parents reported on their positive experiences in using a multimodal treatment approach for their children's ADHD. Use of this approach may have enhanced both parental perceptions of, and experiences in, service utilization. This group of parents seemed to be reasonably satisfied with health care services but for the cost of medication.

A few parents appeared to be somewhat dissatisfied with their children's health care services. There was some indication from their focus group statements that their dissatisfaction stemmed from their frustrations with the providers for not discussing or using a multimodal treatment approach for their children's ADHD. These parents reported that their children's providers were lacking in attention to address both ADHD social problems for children and family problems related to children's ADHD; providers focused too much attention on treatment with medication. The negative health care experiences reported by a few parents who were concerned that providers did not seem to be invested in behavioral treatment to the same degree that they were invested in treatment with medication may be related to the service supply available. Pfefferle (2007) reported on problems in the service supply area for children needing mental health services. These problems included both a short supply of mental health specialists and a great need for child mental health services, and pediatricians reported their own struggles trying to improve access to mental health services for children.

Family and social factors.

Stigma. The family and social factor group that was synthesized from the literature as affecting access to health care services was also represented in the focus group data and emerged in the theme of stigma associated with ADHD in children. The Interview Guide (Appendix B) that was used in focus groups did not include questions on stigma for children with ADHD and their families, but quite a few parents spoke about this problem and its effects on ADHD service access. It is somewhat surprising to find that stigma was yet reported rather frequently because the mental health diagnosis of ADHD among children is fairly common. In addition to parents' reports of stigma negatively affecting these children and their families who were already involved in the ADHD service delivery system, stigma is likely to have affected other study participants who did not report it. The perceptions and experiences of stigma reported by participants in this study are not unlike scholarly reports on effects of stigma for access to services by other population groups. An "anticipated negative treatment from others" was described by Stuber and Schlesinger (2006). According to Gonzalez (2005), stigma is a powerful barrier for access to mental health services.

Part Two: Study Implications

Findings that were interpreted and discussed in the first part of this Chapter separately under the legal method and the focus group method are now integrated by using systems theory as a lens to view important service access problems in the pathways of education and health care, both within and across these pathways. Here, the interpretation of study findings related to policy implementation under IDEA 97 is stretched further in order to examine dissemination of services in light of findings on educational services. Further, the interrelatedness of the education and health care service pathways are viewed by reexamining findings on health care services.

Problems are identified, and strategic recommendations are made for an improved ADHD service delivery system.

Service Dissemination in Education

The first part of this Chapter discussed findings from the legal method that appeared to lend support to IDEA 97 having enabled access to special education services for children with ADHD. The special education legislative policy development of IDEA 97 was consistently implemented by decision makers acting on complaints filed under due process. While this legal process appears to reinforce aspects of successful policy implementation that enabled access to special education services for children with ADHD under IDEA 97, service access problems yet presented in both legal method and focus group method findings for the education pathway.

Lindblom (1980) described many reasons for problems in policy implementation that are presumed to help explain gaps in service dissemination reported in this study's findings on special education service access during the period of time investigated. According to Lindblom, problems of policy implementation include "incomplete specification of the ostensible policy," "conflicting criteria for application," "incentive failures," "conflicting directives," "limited competence," and "inadequate administrative resources" (pp. 65-67).

Parents interviewed in focus groups lacked knowledge about legislation that supported educational services, and they lacked understanding about the service access process. They reported that schools did not always conduct evaluations of children and determine service eligibility. These problematic areas identified are discussed as being in need of attention toward improved service dissemination based on study findings. The study identified some fairly

substantial shortcomings in performance that point the way to substantive messaging for various service delivery system actors. Recommendations for improved service dissemination follow.

Parents lacked knowledge of policy on service access. Relief is first suggested for the perceived contributor to problems in service dissemination of parents lacking knowledge about legislative policy on access to educational services for children with ADHD. Access to services for participants in a different program area was studied, and the research reported contributing effects of parent situations or characteristics, of parent service utilization styles, and of provider outreach styles on service access (Garbers et al., 2006). For example, some parents may be independent and motivated learners who readily gain knowledge about legislative policy and have advocacy skills that are easily transferable to seeking appropriate educational services for their children with ADHD. Other parents may require considerable information, assistance, and support in order to obtain services their children require.

For those parents who are motivated and able to learn about their legal rights and responsibilities independently, service providers can direct them to available resources that will help prepare them to serve as advocates for their children's educational service needs. These resources include (a) non-profit support groups and advocacy organizations that serve parents of children with disabilities, including those specifically focused on ADHD; (b) private individuals and groups who specialize in providing information, training, and/or legal assistance related to children's access to special education services, including service access for children with ADHD; and (c) in the public arena, written materials have been developed and training centers operate in order to distribute special education information without a fee for these services. Many of these resources, both public and private, are also available online.

Although parents may desire educational services for their children with ADHD, it does not necessarily follow that all parents are interested in becoming more knowledgeable about their legal rights and responsibilities regarding legislative policy that supports these services. Or, they may not have abilities to accomplish this. In any case, focus group findings reinforce that parents inexperienced with access to educational services for their children with ADHD need to be able to rely on the expertise of service providers as individuals, schools, or agencies for directing them to service access steps of screening and identification as well as guiding their steps of referral and utilization. Service access problems in eligibility and evaluation reported by these parents may be somewhat resolved today due to the passage of time and the advancement of policy implementation with due process.

School districts sometimes neglected eligibility and evaluation responsibilities. School districts apparently did not always understand legislative policy related to the provision of educational services for children with ADHD under Section 504 or IDEA 97. Efforts are needed in the education pathway for maintaining and developing understanding of school districts' legal rights and responsibilities regarding the provision of these services. Complaints filed on behalf of children with ADHD did expand policy implementation in this area under IDEA 97. However, both the prevalence and the incidence of ADHD in children necessitate ongoing vigilance from school districts to evaluate them and determine their eligibility for special education services when they present with its problems and are suspected to require these services. Recommendations for improving service dissemination are also made surrounding the role of school districts' key actors in policy implementation, school district administrators.

School district administrators. School districts have legal responsibilities to locate, identify, and evaluate children in their jurisdictions who are suspected to have eligible

disabilities and who may require special education services. Following IDEA 97, children with ADHD could be legally considered under OHI for special education eligibility when they were thought to be in need of these services due to their ADHD. Under current special education legislative policy, this right continues today for children with ADHD. An evaluation is required to determine if the disorder adversely affects a child's educational performance to require special education services. School districts are responsible for conducting these evaluations and determining eligibility for children thought to be in need of services. Special education legislation places the burden of responsibility on school districts to locate, identify, and evaluate children for services, and school district administrators should not rely on parents to carry this burden.

School districts will still require help for understanding, interpreting, and implementing policy on access to educational services for children with ADHD under civil rights and special education legislation in substantive areas of eligibility for services, evaluation, change of placement, and sufficiency of services. School district administrators require current information in these policy areas. They have responsibilities to stay informed on these policies and can use a variety of resources to do so: continuing education, professional literature, professional organizations, online special education and legal resources, and consulting with legal service providers retained by school districts.

School district administrators should work toward preventing disputes from arising between districts and parents, consulting with their school social workers who are knowledgeable about these policies, skilled in communication and mediation, and more familiar with school district children in need of services. They can take a proactive approach in service provision by encouraging school districts to improve outreach efforts, such as distributing key

school personnel contact information for parent questions about educational services and providing meeting space for parent support groups related to children's disabilities or educational service needs. These administrators can demonstrate their commitment to avoiding unnecessary conflict between parents and schools regarding children's access to educational services, such as hosting public information law forums on special education topics at schools to benefit all stakeholders.

Since this study was conducted, both other federal educational policy and other state or school district initiatives have developed that benefit the educational service needs of children. However, this new policy and the additional educational initiatives do not replace the educational services rights of children with ADHD under Section 504 and current special education law. School districts continue to have responsibilities regarding these educational service rights for children with ADHD.

School social workers. School social workers also have an important role to play in interpreting educational policy for parents and encouraging them to seek appropriate services for children with ADHD. They can help parents understand the service routes available and explain the services to be expected under each route. They can explain to parents that other options for educational services may be available when a school district's evaluation finds a child ineligible for special education services, such as voluntary extra help from the child's classroom teacher or accommodations and modifications under Section 504. School social workers can help establish parent support groups in areas where none exist. These groups can aid in disseminating information about legal rights and responsibilities regarding access to educational services and promote understanding about using these services, in addition to providing other information and support for parents facing children's ADHD problems.

Health Care Services

The study findings indicated a need for continuing advocacy, coordination, and collaboration in educational and health care services in order to sustain and improve service access for children with ADHD. This section again uses systems theory as a lens to view implications that follow from the discussion of study findings, taking an integrated look at service access problems in the health care pathway directly and in light of its interrelatedness to educational services. Recommendations for improving access to services are made in the following areas: insurance, multimodal treatment and medication, and stigma.

Insurance. Although findings for this study did not indicate widespread problems of children with ADHD being without health insurance coverage, findings did reinforce the importance of having this insurance for access to ADHD health care services. Social workers in both service pathways can work with families toward improving children's access to ADHD health care services by explaining to parents the importance of having health insurance and encouraging them to obtain it. They can help parents enroll children in the State Children's Health Insurance Program (SCHIP) or in public assistance health insurance plans, working directly with parents in order to complete application forms or referring parents for assistance with the application process.

Research on access to health care services has identified particular subpopulations of children in need of improved insurance coverage. Social workers in both pathways should be mindful of reported groups of children who particularly lack health insurance coverage and should strive to improve health insurance enrollment for these groups of children, including children with ADHD who will be among these groups. Yu et al. (2001) discussed the need for

expanding outreach to enroll more children who are immigrants in SCHIP in order to improve their access to health care services. A study by Raghavan et al. (2006) cautioned about using carve-out insurance plans for the provision of mental health services to children who are clients of the child welfare system, as these children may be better served with other types of plans due to their more frequent use of mental health services.

Multimodal treatment and medication. Two service access problem areas were identified in the health care pathway and present opportunities for improvement: parental interest in multimodal treatment for their children's ADHD and parental concerns about paying for medication to treat their children's ADHD. Social workers in health care, particularly those employed by pediatric clinics or community mental health agencies, can help parents understand the benefits of using a multimodal treatment approach and can advocate for children with ADHD to make this form of treatment more widely available. These social workers can also coordinate and collaborate with school social workers in promoting multimodal treatment that includes training for parents in behavior management of children with ADHD, implementing this training with community- or health care-based workshops.

Social workers employed by pediatric clinics or community mental health agencies can work collaboratively with pharmacists, nurses, physicians, and other health care providers in giving parents information on medication or other interventions that are included in a child's health care treatment plan for ADHD. Further, these social workers can try to minimize the financial stressor of medication costs borne by parents to treat ADHD in children. They can do this by becoming familiar with medication assistance programs that help pay for medication costs not covered by insurance and by referring parents to these programs where they are available. Such programs may be offered as charity care assistance through health care

institutions, community agencies, and non-governmental organizations. Corporate pharmaceutical programs are also sometimes available to provide assistance with the medication costs. Disseminating this information about resources that may help with medication costs through patient health care networks, parent support groups, and colleagues in educational services could prove beneficial for families.

In addition to health care social workers contributing in the above areas for an improved children's ADHD service delivery system, other health care service providers may be able to offer assistance in these areas, particularly when social workers are not available. For example, small group physician practices may not employ social workers on staff. In addition, school social workers may encounter opportunities while interacting with parents for encouraging a multimodal treatment approach that includes any educational supports or services determined necessary for a child with ADHD. It is important for parents to recognize contributions from both service pathways in working toward improved well-being and school success for children with ADHD.

Stigma. Another area that requires attention for improvement in the service delivery system for children with ADHD and their families arises related to ADHD being a diagnosed mental health problem. This is the problem of stigma, and it affected access to services in both of the service pathways studied, education and health care. Parents described their perceptions and experiences of stigma both for the children with ADHD and for the families of these children. They reported problems of stigma primarily in the pathway for educational services. However, the parents interviewed in focus groups had already made decisions to seek health care services for their children's ADHD. The unknown effects of stigma on other parents in coming to their

decisions about seeking health care for their children because of suspected ADHD were not studied but are expected to exist as negative effects on access to these services.

Social workers and other service providers in education and in health care should be aware of the negative effects of stigma surrounding ADHD in children, and should offer emotional support to them and to the children's families. Further, social workers and other providers in both service pathways should intervene as needed when parents require education on symptoms and problems of ADHD in children for making informed decisions about seeking help for a child suspected to have ADHD, as some parents may hesitate to seek help for their children with ADHD because of stigma. Social workers and other service providers can also work to reduce the stigma surrounding this mental health condition. This advocacy could include implementing social media campaigns that are designed to combat the stigma surrounding ADHD as well as other mental health conditions, adapting national mental health education programs for local use.

Area of Strength across Service Pathways

In addition to discussing the needed service improvements above, a source of strength in the service delivery system was evident from integrating study findings across the service pathways. This strength was that good communication between providers as well as between providers and parents did appear to improve the service utilization step of access for children with ADHD who received services. Participants provided examples of this occurring in each pathway as well as between pathways. The frequent use of child behavior and learning assessment forms to share information between the service pathways was beneficial for children's access to services in each of the steps drawn from Powell et al. (2007): screening,

identification, referral, and utilization. It also illustrates the interrelatedness of the education and health care pathways, with each pathway providing services that complements services of the other pathway to benefit children with ADHD.

Social workers and other providers of educational and health care services in schools, clinics, agencies, and private practice can act broadly to help children with ADHD and work toward improving services for this group of children and their families. The collegial effort among social workers and other professionals in working toward improving services for children with ADHD is consistent with improving service outcomes as described by Tapper et al. (1997). They described the benefit of coordination and collaboration among service providers when working toward common goals in service delivery.

Closing Section

Study Limitations and Benefits

Despite limitations of the dissertation, its social epidemiology approach that used two methods to study children's access to educational services surrounding a change in educational policy for ADHD provided important findings. Access to educational services under educational policy for children with ADHD was studied because these services are considered to have a broad positive effect on their health and well-being when they can appropriately use services toward improved school outcomes. A substantial part of the work investigated access to educational services under special education legislative policy development that was expected to favor their access to these services for ameliorating their academic and social problems related to ADHD.

Legal method findings reported on the major problem areas of complaints filed over a sufficiently long period of time in order to allow some of the important educational service access issues for children with ADHD to be identified. Findings reported from studying these complaints are not considered to reveal the nature of all complaints filed for children diagnosed with ADHD and are not used to draw conclusions about the frequency of problems with access to services in the education pathway. Nonetheless, collecting and analyzing retrospective complaint data from a 12-year period of time built knowledge that improves our understanding about the nature of disputes between parents and schools regarding educational services for children with ADHD. Studying these complaints allowed reporting on some important issues by categorical problem areas and describing issues in the context of legislation supporting educational services for children with ADHD. This attention to the content of past disputes informs school districts and other stakeholders on responding appropriately to educational service needs of children's ADHD school problems. Little research was done in this area before this dissertation.

The legal method was limited by reporting on those complaints filed by parents or school districts and subsequently published in the *Individuals with Disabilities Education Law Report* (IDELR). No systematic method existed for tracking all complaints filed. Complaints regarding the education of children with disabilities were kept by state or federal agencies. However, not all complaint decisions were reported to a database with public access. Therefore, a representative sample of complaints could neither be drawn from all complaints filed during the time period studied nor be drawn from complaints for children with ADHD filed during the time period studied. There was also no method for estimating how closely the 121 complaints available to study resembled a representative sample.

The exploratory design and small convenience sample of the focus groups prohibit any generalization of findings on parents' perspectives regarding access to educational and health care services for their children with ADHD to the larger population of parents and their children with ADHD. One might argue that drawing the sample of parents from those who attended support groups was biased if dissatisfaction with services for their children was the reason that they attended support groups. However, one might also argue that parents attended support groups because the problems of ADHD were new for them and that they sought information and support related to a child's diagnosis of ADHD. Or, one might also argue that parents attended support groups because they were experienced with the problems of ADHD in their own children and that they attended as advocates for children with ADHD because they wanted to pass on their knowledge, experience, and support to other parents. Regardless possible reasons for parents having attended support groups, their open sharing of service access perceptions and experiences in this study are a valuable contribution.

The focus groups findings are useful when considering the service needs of children and families in similar situations, toward securing services for reducing disability due to ADHD. The findings are also helpful for guiding other research. Although no direct benefits were promoted to the individual parents who participated in the focus groups, discussing service access issues may have stimulated some of the parents to become more proactive for the special needs of children diagnosed with ADHD.

Future Research

Children with ADHD may require special education services if the condition adversely affects their educational performance or may require educational services in the form of accommodations and modifications if the ADHD substantially limits their ability to learn.

Schools must evaluate children with ADHD if they are suspected to require special education services and determine their eligibility for services. Future research is needed that examines more recent legal complaint activity under both service access routes in order to identify persistent and emerging issues disputed under current legislation. In addition, investigating changes in the distribution of complaint problem categories for a particular school district could provide valuable evaluation information despite the unavailability of such data nationwide for large scale epidemiological studies.

An individual interview method used with parents of children receiving services under either access route may reveal additional strengths and weaknesses of the service delivery system that were not uncovered by studying complaints retrospectively or by conducting focus groups. The perspectives of school district administrators, teachers, and school social workers on service provision for children with ADHD are also important, and data could first be collected in focus groups from these stakeholders in order to identify areas of the children's ADHD service delivery system that require more in-depth study. In health care, a more detailed and updated study that includes the perspectives of parents and of health care professionals regarding the utilization of multimodal services is needed. This could be accomplished with a study design that uses both survey and individual interview methods.

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APPENDIX A

BACKGROUND INFORMATION

1. I am the parent or guardian of a child diagnosed with ADHD at age ____.
2. Besides ADHD, my child has also been diagnosed with _____.
3. My age is ____.
4. My sex is ____.
5. My race is ____African-American ____White/Non-Hispanic
 ____Hispanic/Latino ____Native American
 ____Asian ____Other
6. My marital status is ____married or living with partner ____never married.
 ____separated. ____divorced. ____widowed.
7. What is the highest grade of school you ever completed? ____
8. My child is a ____boy ____girl.
9. My child attends _____ School, which is ____public ____private
10. My child is ____ years old.
11. My child is in ____ grade.
12. Do you know about Section 504? ____yes ____no
13. Do you know about IDEA of 1997? ____yes ____no
14. The school evaluated my child for services because of ADHD. ____yes ____no
15. I requested services for my child at school because of ADHD. ____ yes ____no
16. My child has received services at school because of ADHD. ____yes ____no
17. My child takes prescription medications daily for ADHD. ____yes ____no
18. Our household during the year 2003 included a total of ____ children and ____adults.

19. Our total household income during the year 2003 was about \$_____.

APPENDIX B

INTERVIEW GUIDE

1. (K) Tell me how you think ADHD impacts your child's education. What is your understanding of laws about schools providing services to children with ADHD?
2. (EF) Did the school ever contact you with concerns about your child's academic progress or social adjustment? Did you request an evaluation from the school for your child with ADHD so that (s)he might be able to receive additional educational services at school? Was an evaluation completed? Did you seek an evaluation privately?
3. (EX) Please describe any educational services your child receives at school as a result of his/her ADHD diagnosis? What impact have the services had on your child's academic progress and social adjustment? Tell me about your experiences in using those services.
4. (EX) What educational services (e.g. tutoring, reading improvement, study skills, social skills training, etc.) does your child receive privately? Why did you seek out these services privately? How do you pay for the services?
5. (EF) Has the school referred your child to services not offered at school but that they thought might be helpful because of his/her disorder (such as health care, special recreation, family support services, etc)? Are there other types of services that you thought the school should have referred you to?
6. (EF, EX) If referred by the school, please tell me if you followed-up on the referral and got help in any of those areas, and about your experiences with any help received. How were those services paid for? If you did not follow-up on a referral, why didn't you?

7. (EX) Please describe the health care your child receives from his/her primary doctor for ADHD? How do you pay for this care? Does the doctor's office communicate with the school about your child's medication(s) or other treatment issues?
8. (EF) Have you asked your child's primary doctor for a referral to additional medical or mental health care, or to educational services? Was the referral made? Did it lead to services? Was a referral made that you didn't request? Did you follow-up on it?
9. (K, EX) I'd like to hear about any other services that your child or anyone in your family received because of your child's ADHD (such as counseling, behavior management, parent classes, etc.). How did you know about the services? Where did you go to get them? Who paid for them?

Access abbreviations: K=knowledge, EF=effort, EX=experience

APPENDIX C**DISABILITY ACRONYMS**

ADHD: Attention-deficit/hyperactivity disorder

FAPE: Free appropriate public education

IDEA 97: Individuals with Disabilities Education Act Amendments of 1997

IEE: Independent education evaluation

IEP: Individualized education program

OCR: Office for Civil Rights

OHI: Other health impairment disability classification